

Evaluation Report of Kooth's 'Help to Cope' Integrated Digital Pathway (IDP)

Pilot with Lincolnshire Partnership Foundation Trust CAMHS Crisis and Enhanced Treatment Team (CCETT)



April 2024

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Executive Summary

In 2O23, urgent referrals of young people (YP) to mental health crisis teams in England and the number of YP awaiting support from Child and Adolescent Mental Health Services (CAMHS) both reached an all-time high (<u>NHS Digital</u>, 2024). To explore the potential for digital mental health services to extend the capacity of crisis services and provide alternative routes to support for more YP, Kooth, Lincolnshire Partnership Foundation Trust (LPFT), CAMHS Crisis and Enhanced Treatment Team (CCETT) and Lincolnshire County Council (LCC) worked collaboratively to develop a care pathway, 'Help to Cope'. This pathway aimed to take pressure off CAMHS and CCETT by decreasing their waiting list and providing a digital alternative to more immediate access.

Development and mobilisation of Help to Cope was undertaken rapidly, with a highly collaborative approach to service design which enabled the pathway to launch in under 16 weeks. This was underpinned by existing trusted relationships between local NHS and Kooth teams, with Kooth's existing digital mental health service embedded in the local system for a number of years.

Key Highlights:

• 100% of YP who completed their intervention indicated that they felt heard, understood and respected in their chat. YP who engaged were satisfied with support provided and positive outcomes can be demonstrated.



• **82% of referrals received into the pilot were eligible.** Of those who were eligible for the pathway, **77% engaged with the digital support offered.**



• YP who engaged with the pathway had presenting issues relating to anxiety, stress, suicidal ideation, self harm, family relationships, school and college and depression/low mood.

• 100% of YP indicated that they felt the practitioner helping them was a good fit for them and 83% indicated that the session felt right for them at the time.

• 3 in 4 YP indicated that they would recommend Kooth to a friend.

• Differentiating features of the Help to Cope pathway were popular, for example the out-of-hours support (beyond the traditional 9am-5pm) was highly utilised, with **82% of chats attended being out-of-hours**.

• An average of 7 therapeutic messages (asynchronous and outside of live chat) were sent to YP who used messaging for support. YP were highly engaged in the 'keeping well' elements of the pathway which provide a popular and flexible option to receive therapeutic support from a professional.

• Goals were set around YP's wants; improving emotional wellbeing, personal development and resilience or receiving support around their relationships. 53% of goals that were engaged with achieved meaningful change for those YP.

• **37% of referred YP were young carers**. This is thought to be correlated to the flexible nature of the support offered through the Help to Cope pathway.

• The **Kooth practitioners** who supported this pilot reported that they felt **comfortable, supported and boundaried within their role.**



CCETT staff have recognised the importance and usefulness of the pilot pathway in offering support either upon discharge from CCETT or while waiting for stepped-down support from CAMHS.



For referrals to be deemed as appropriate, YP were identified to have certain presenting issues or needs along with other criteria:

- Mild-moderate mental health problems e.g., low mood, anxiety, superficial self-harm, emotional dysregulation.
- Low-medium risk of harm to self with no known suicide attempts within the last 6 weeks.
- Willing to engage in online interventions and access a digital platform.

There was a strong integrated and collaborative approach to this pilot, with strong positive outcomes, reflecting the collaborative processes and working relationship between CCETT and Kooth's Service Delivery and Safeguarding Teams. The safeguarding procedures and examples of this have demonstrated the safety in digital care pathways, with no challenges highlighted in the safeguarding processes.

Referrals were largely appropriate, yet referral quantities from CCETT to this pathway were lower than anticipated and predicted. Through the process evaluation, it was identified that the referral technical process requires improvement. Kooth has started investigating technical solutions to improve the referral flow from CCETT to Kooth, in the future. In integrating two services, technical processes are bound to need improving. This pilot has also highlighted that building confidence in novel approaches, especially digital ones, requires time. We recognise that a clearer referral criteria and a smoother process would



have supported CCETT staff in feeling more confident in how and when to refer YP to the pathway. Providing additional staff training could have improved support. This, as well as dedicating more time to implementing and ramping up the pilot program, rather than just focusing on service delivery, would have been preferable. However, limited time and resources from services like CCETT posed challenges to effective implementation, and the representatives from CCETT have provided as much support as they could. Technical solutions could have also supported the referral process and reduced disengagement by addressing delays in sending and receiving referrals, leading to additional follow-up actions from CCETT and Kooth. We recommend that these technical processes are addressed before implementing integrated pathways to give the pilots the best chance of success.

The Help to Cope pilot ran for a short 8-month period, including a ramp-up period, while implementation and training to make referrals was ongoing. The pilot has provided some early indicators of a suitable and acceptable care pathway for YP stepping down from crisis support with CCETT. Once referrals were accepted, there was rapid contact from Kooth to conduct an assessment, removing the need for YP to be on a waiting list. Once YP engaged with chats, attrition was very low and therefore adherence was good. However, recommendations have been made to improve the referral process, to increase the impact and scalability of this pilot, and to improve its clinical utility and systemic impact on Lincolnshire's CCETT capacity.



Introduction

A mental health crisis is defined in Mind's (2010) report 'Listening to experience' as when someone "is in a mental or emotional state where they need urgent help" (p. 12). Urgent referrals of young people (YP) to mental health crisis teams in England and the number of YP awaiting support from Child and Adolescent Mental Health Services (CAMHS) both reached an all-time high in 2023 (NHS Digital. 2024). A multi-agency review conducted by Rhodes (2018) of mental health services in Lincolnshire highlighted the huge demand on the CAMHS service and specifically the crisis team, and identified barriers to support including accessibility issues, oversubscription and staff shortages.

Kooth has provided pioneering digital mental health services to the NHS, Local Authorities, and other Health and Social Care providers since 2001. Kooth's BACP-accredited platforms are now available to over 15 million people, with over 500,000 users, 100,000 individual stories shared, over 1 million hours of professional support delivered - and Kooth continues to innovate in the space. Working within the context of the Thrive Framework (Wolpert et al., 2019), Kooth has supported improved outcomes for YP since our online service was commissioned in Lincolnshire in 2018 through Lincolnshire County Council (LCC). Through this work, they have developed a robust understanding of the clinical needs of Lincolnshire YP - the data suggest a higher than average rate of suicidal and self-harm risk factors in YP from this area, and our figures on risk de-escalation in these groups reflect Kooth's successes in safeguarding these users.

Continued collaboration between existing face-to-face support and Kooth may provide a flexible and needs-led approach to mental health challenges such as crisis support, whilst also meeting YP preferences for flexible and accessible support outside of clinical settings (Vusio et al., 2019; Dutton et al., 2023; Edwards et al., 2023). Kooth's novel Help to Cope pathway was designed to work alongside LPFT, CAMHS Crisis and Enhanced Treatment Team (CCETT) to support children and YP at risk of or currently experiencing a mental health



crisis, with a focus on reducing admissions to specialist CAMHS services and supporting existing pathways.

Successful digital and face-to-face collaborations require a robust understanding of the purpose and scope of the collaboration, and the efficient development and integration of the processes such as effective referring and safeguarding (Unsworth et al., 2021). This report aims to provide an evaluation of Kooth's Help to Cope pilot pathway, to learn from the development and implementation of this pathway, and reflect on the challenges and successes. Outcomes of the support provided will be explored, with an acknowledgement of the short period of the pilot limiting the outcomes that can be explored. The report is split into three key sections; process and outcome evaluations and recommendations for any new pilots.



Process Evaluation

Process evaluations are integral to understanding how a pilot pathway such as Kooth's Help to Cope Integrated Digital Pathway (IDP) has been implemented. The focus of this report's process evaluation will be how the Help to Cope pathway was established, through cooperative efforts, by innovating on Kooth's classic platform. Key aspects of this process evaluation will be the referral pathway and our safeguarding procedures.

How was Kooth's Help to Cope pathway designed and implemented?

There was an initial pilot proposal document that was developed to outline the whole project and a specification drawn up from LCC, who were the commissioning organisation who contracted us to deliver this.



Timeline of the Help to Cope Pilot: From commissioning, to implementation and evaluation

October 2022	January 2023	Early March 2023	Late March 2023	May 2023	June 2023	July 2023	December 2023	March 2024
The Kooth model and how it supports crisis intervention is presented to Midlands AHSN.	Lincolnshire commissioner notifies Kooth of pilot opportunity.	Lincolnshire IDP Crisis Pathway Pilot internal Kooth group formed to review specification and develop initial model, referral criteria, delivery, resources and outcomes over weekly meetings.	Kick off meeting with LCC, CCETT Managers and Project Lead to start project planning then fortnightly project meetings until May.	Lincolnshire IDP Mobilisation Meetings with LCC, CCETT and Kooth leads. Fortnightly meetings until July and Go Live date.	Go Live date agreed with the implementation period starting.	Implementation period ended. Referrals accepted. Lincolnshire management and monitoring meetings commenced.	Mid-pilot evaluation surveys shared with CCETT practitioners, Kooth practitioners and managers and YP. Interim Evaluation data requested from CCETT and Lincolnshire commissioners.	Pilot ends, fina evaluation report refreshed with new data.

The estimated time dedicated to the Help to Cope IDP was very high in comparison to other commissioned projects due to the high level of involvement from senior Kooth staff members from a multitude of teams. This was required to rapidly respond to the service specifications and ensure YP safety, as well as ensure legal compliance, technical solutions for the referral processes and development of the joint working procedures. Significant time was given from the Head of Service Delivery, Director of Clinical, Head of Clinical, Head of Research, Head of Safeguarding alongside service managers, safeguarding leads and product developers. This was possible due to the existing infrastructure of Kooth as a digital provider with resource to allocate to rapid and small pilots. CCETT also contributed a lot of time and resources into the pilot development, which has ensured the pilot's successful implementation.



Summary of the Specification:

Kooth was commissioned across Lincolnshire to provide early intervention and prevention to 11-18 and up to 25 for care leavers. Kooth further enhanced this offer by delivering a pilot for 6^1 months to support NHS Lincolnshire CCETT in providing online structured support as proof of concept 'The impact of Digital Provision on Crisis Provision'.

Kooth worked with CCETT to support children and YP at risk of or who had experienced a mental health crisis, with a focus on reducing admissions to specialist CAMHS Tier 4 services and supporting existing pathways.

It was agreed that CCETT would undertake an initial assessment to understand the presenting issues, level of risk, Gillick Competence and determine suitability for referral to Kooth for digital provision of support.

There was then a requirement for Kooth to address the following criteria:

- Provide individuals with the opportunity, through appropriate support and guidance, to prevent or help manage a crisis episode in line with the service referral criteria. Support offered must follow an evidence-based model.
- Provide the opportunity to immediately source the appropriate level of support when individuals have been assessed by crisis. This will follow a sign up process and a welcome letter shared with the YP once the referrals have been received by Kooth.

Criteria for Referral:

In scope were YP aged 11-18 years and up to 25 for care leavers, who had accessed CCETT through A&E or the Mental Health Leads. Kooth's model primarily supports YP with the following presenting needs which will be deemed appropriate for referral such as:

¹ Originally 6 months but extended due to initial implementation facing technical and legal delays, therefore the pilot lasted for 8 months.



- Mild-moderate mental health problems e.g., low mood, anxiety, superficial self-harm, emotional dysregulation.
- Low-medium risk of harm to self with no known suicide attempts within the last 6 weeks.
- Willing to engage in online interventions and access a digital platform.

This referral document was collaboratively created and jointly agreed with LCC Commissioning Officers and LPFT, CCETT Managers and Project Leads, Kooth SD Head of Service, Clinical Leads, Research and Commercial Leads.

The more detailed eligibility and referral criteria was further developed at fortnightly meetings with the same team where key processes were co-designed:

- Help to Cope IDP Joint Working Processes
- Help to Cope IDP Referral Form
- YP Informational resources about Help to Cope and Kooth
- Sign up and Flow Process documents specifically for Help to Cope



What support do the young people referred to Kooth's Help to Cope Pathway receive?

The support offered to YP through Help to Cope (see Figure 1) incorporated not only professional contact with a trained practitioner but also flexible and autonomous wellbeing support and safety management, with the YP at the centre of what wellbeing tools they engaged with. A key part of Kooth's Help to Cope IDP pathway was the **'keeping well' support** which has demonstrated to be a significant source of wellbeing support for YP (<u>Stevens et al., 2022</u>). Importantly, alongside this, YP agreed to engage in a **structured chat intervention** which offered synchronous, text-based sessions. Chat sessions could be either weekly or bi-weekly and either inside or outside of traditional working hours. Additionally Kooth's **crisis prevention support** was designed to empower YP to prevent escalation to a mental health crisis through safety and wellbeing planning as well as goal-setting. Lastly, this pathway provided **safe crisis management** which was achieved through robust safeguarding procedures alongside collaborative risk escalation and management.

'Keeping Well' Support

Access to our website for self-help, articles and peer support was available 24 hours a day, 7 days a week.

Additional asynchronous therapeutic messaging was available with a practitioner.

Structured Chat Intervention

Access to up to 6, online structured counselling chat sessions, once or twice a week.

This was available Monday – Friday 12 noon to lOpm, and Saturday and Sunday 6pm-lOpm

Crisis Prevention Support

YP were provided with the opportunity, through appropriate support and guidance, (such as goal-setting and safety-planning) to prevent or help to independently manage a crisis episode

Safe Crisis Management

Robust safeguarding procedures which made full use of existing personalised support routes and personal information held to keep YP safe when presenting in crisis on our site.

Figure 1: Types of support offered through Kooth's Help to Cope pathway.



How does Kooth effectively safeguard young people on this pathway?

Prior to the commencement of the Help to Cope Integrated Digital Pathway (IDP) pilot, a comprehensive Integrated Digital Safeguarding Pathway and statement were formally established and mutually agreed upon between Kooth and CCETT, led by Kooth. This pathway described how Kooth intended to safeguard users, and work with external professionals and services, in particular Lincolnshire CCETT.

The IDP Safeguarding pathway was aligned with Kooth's existing and robust Safeguarding policies and procedures. However, it deviates slightly from Kooth's standard approach due to a number of tailored features, including weekly liaison with the CCETT team and the ability to rapidly re-refer YP in the event of an escalation in risk during their initial engagement.

A key distinction also lies in holding personal identifiable information and safety plans for each YP, which allowed the IDP service delivery and clinical team to escalate significant safeguarding concerns without delay. The safeguarding processes and escalation is demonstrated in Figure 2.



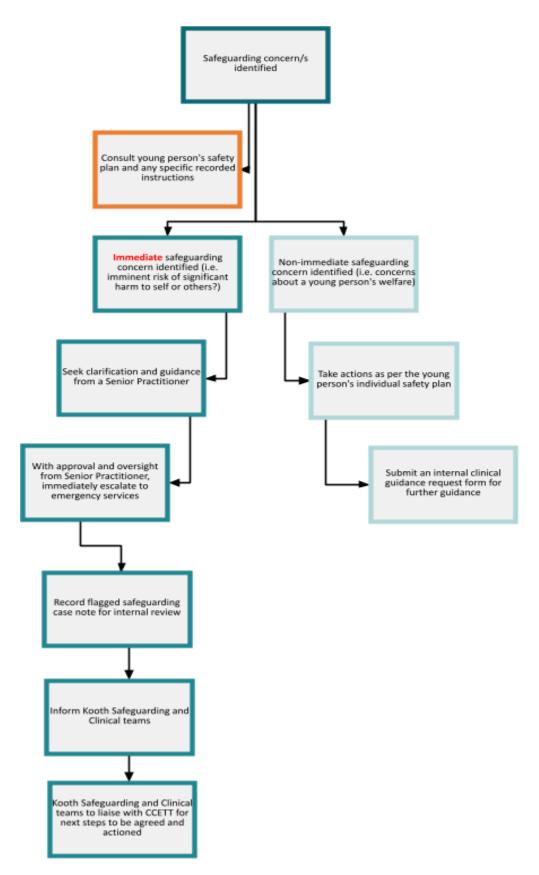


Figure 2: A flow diagram of Kooth's Help to Cope Safeguarding escalation pathway.



How does Kooth's safeguarding process work <u>for</u> young people in practice?

The case represented below (see Figure 3) exemplifies key components of successful safeguarding in the pilot of the Help to Cope pathway in Lincolnshire; trained practitioners assessing the risk presented by a YP via text-based communication, sharing of risks and personal information held between digital and face-to-face support (underpinned by robust contracting - where the YP were made aware of their lack of anonymity and how we would use their information to keep them safe prior to their intervention starting) (Da'Bell, 2022).

Importantly in Kooth's Help to Cope IDP pathway, safeguarding has continued past the disclosure that triggered an external intervention - the practitioner would utilise internal support offered by Kooth Safeguarding and Clinical teams and continue to assess risk at each interaction. The practitioner would collaborate with the YP to develop a safety and wellbeing plan - a preventative and empowering approach to crisis de-escalation. The safeguarding undertaken in this case was key to the YP's positive outcome.



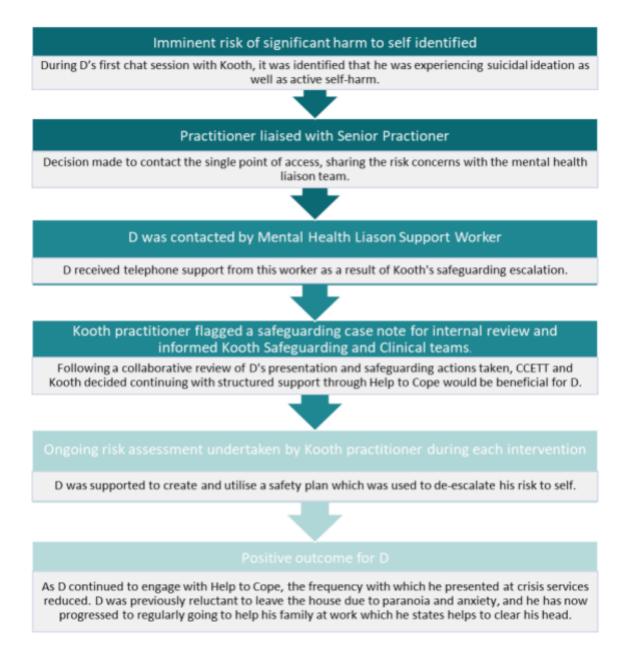


Figure 3: Example of our safeguarding process in action - Case Study D.



Kooth practitioners involved in delivering the Kooth Help to Cope pilot have unanimously provided positive feedback regarding our Integrated Digital Safeguarding Pathway.

The Kooth practitioners who supported this pilot provided feedback that they felt comfortable, supported and boundaried within their role. The implementation of weekly meetings between practitioners and the Kooth Safeguarding and Clinical team-members has been highlighted as a positive source of support for practitioners.

The collaborative nature of Kooth's safeguarding process also allowed for external, multi-disciplinary discussions around how YP could be best supported in both face-to-face and in a digital setting such as Kooth.

'Having personal identifiable information 'The support from clinical and safeguarding allows practitioners to be confident in what [teams] during the pilot has been great. The we can offer the young people and how we weekly meetings and review meetings have can keep them safe' been positive and helpful.' Kooth Practitioner Kooth Practitioner 'We are in contact with the team that referred the YP which is extremely helpful in understanding the assessment of risk and need. It allows for continuation of shared care and clinical communication/decision making. If there is an increase in risk we can manage this effectively with the YP in mind i.e. step up/down process. There is a *fluid feel* to accessing support. We can also ensure YP are kept safe as if there are any SG risks we can immediately escalate this. The YP and families have consented and are well informed in regard to what to expect. There is opportunity to share any further concerns or need for continued support and care with the wider services such as GP. For example if through our work we identify that a YP might in fact benefit from therapy we can advice and evidence why we think this.' Kooth Manager



Focus on: the referral process

How were young people referred into Kooth's Help to Cope Pathway?

YP who were referred to Kooth's Help to Cope pathway were referred by Lincolnshire CCETT. Legal data sharing agreements were implemented by Kooth and Lincolnshire CCETT prior to any referrals taking place. As seen in Figure 4, following referral, the YP's suitability for the pathway was assessed and the pathway was discussed with each YP to determine patient preference and choice. YP then provided consent and collaboratively worked through the referral form, and were supported to create a Kooth account. A robust safety plan was developed between CCETT and the YP (if not previously completed), and this, along with the referral form, was shared with Kooth via a secure Microsoft Teams Channel. This process highlights the support provided to the YP to ensure that they feel comfortable and confident in making contact with Kooth.

Handover calls were conducted between Kooth and CCETT to review and accept the YP. Once accepted, Kooth practitioners would reach out to YP via asynchronous message within the Kooth platform, to arrange a chat at a time that suited the YP, including out-of-hours (beyond the traditional 9am-5pm) options.



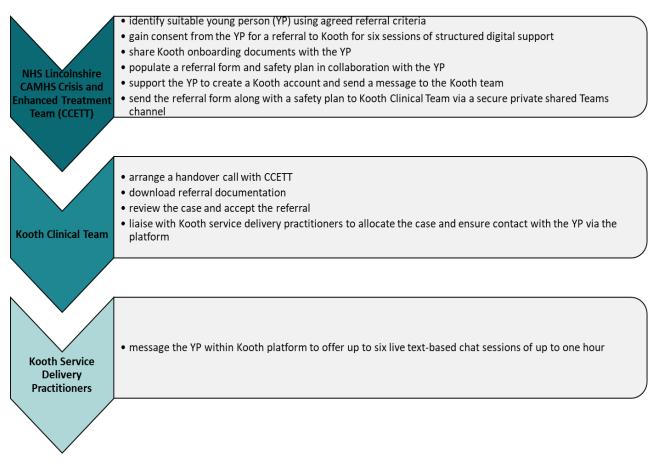


Figure 4: Schematic of the referral pathway from CCETT to Kooth's Help to Cope as part of Kooth's Integrated Digital Pathway

Strengths of the referral process identified from staff surveys:

The referral process had a predetermined target population and clear purpose; to provide step-down care for those leaving a crisis service. The continuation of care provided stability to YP and more support to Kooth practitioners who could escalate when necessary due to the connection with the CCETT team. The referrals made into Kooth have been widely considered to be appropriate.





Challenges & weaknesses of the referral process:

Integrating across traditional face-to-face and digital services has provided some challenges, in particular relating to data sharing between NHS and private organisations. The bespoke referral process implemented for Help to Cope has been highlighted as a barrier to YP engaging with this pilot, with the following issues identified:

- Requirement for YP to confidently access Kooth's Help to Cope digital platform.
- Time taken to send and receive referrals into the pathway was longer than expected this leads to additional follow-up actions from CCETT and Kooth and may be contributing to YP disengagement.
- Referrals being sent through insecure channels.
- Potential to improve CCETT staff confidence in referring YP to Kooth Help to Cope pathway.

These issues have been raised through the following channels:

- Regular internal (Kooth) and external (Kooth, Lincolnshire Commissioner, CCETT) meeting logs -
 - Held to identify any barriers to the success of the pilot. Suggestions for improvement were discussed and collaboratively agreed. A risk assessment for each item was undertaken and resultant actions were allocated.
- Mid-point survey responses -
 - CCETT and Kooth staff involved in the pilot were invited to participate in mid-point surveys designed by the Kooth Research Team to share their insights into how the pilot was progressing. (See Appendix 1: Data Collection Procedure)

Thematic analysis of the logs from these meetings and the mid-point survey responses, alongside quantitative analysis of referral data has been undertaken, with key learnings presented in Table 1 below.



Table 1: Key challenges, improvements made and actions taken in relation to referral-pathway related issues - results of a thematic analysis of weekly meeting logs, mid-point interview responses and referral data.

Source	Identified issue	Improvements	Status
Weekly meeting log analysis	In order to access support through the Help to Cope pathway, YP required access to digital means and ability to navigate the platform.	 The referral form included information-capture questions about digital capabilities and any communication needs. The referral team liaised with Kooth's clinical team regarding YP's suitability for the pilot. If required, YP were offered support to complete the registration process. 	



Weekly meeting log analysis and mid-point survey response analysis	Sending and receiving secure referrals was taking longer than would be preferred. Time between referral and confirmation of sign-up with Kooth highlighted as longer than expected and requiring additional actions from CCETT to chase - 'they [YP referred] have needed repeated follow up to complete registration and make initially contact' - CCETT Practitioner	restricted the identified as cor - Managers and CCETT and adjustments to dedicated verifi- parental involve of push notifica with YP's progre - 'I think that we by asking child consent to cor introductions/he think it would b in the process i along the way a know and care We could also o appointments notification on	censing agreements have flexibility of the process ntributory factors. practitioners from both Kooth have suggested the referral process - a ed portal, consideration of ement in sign-up, and use ations to keep up to date ess through the pathway. e could improve our service fren and parents for their ntact them and complete elp with sign up. I also be useful to include parents .e. update and inform them as they are the people who about their children most. contact to remind them of as there is no push Kooth - which I believe ment.' - Kooth Manager	Action -	ed and Ongoing Kooth are pursuing the use of a portal system for teams to send/receive referrals (OLM Systems). Kooth team continues to provide updates regarding NHS secure mail/becoming a trusted NHS provider to obtain a licence for the LPFT Teams Platform.
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		 'It would be great if we could email/text a service user to let them know when we have sent a message as they often miss that as we have no way of notifying them and I feel this would hugely improve engagement' - Kooth Practitioner 	
Weekly meeting log analysis, mid-point survey response analysis and referral analysis	not consistently used the	 Breach reported through Datix. Need for additional training for referring practitioners identified. CCETT managers and practitioners suggested further training and improved access to referral criteria guidance to aid them to feel more confident in referring to the pathway - 'Information around what happens following referral to Kooth and what the process is.' - CCETT Practitioner 	session was delivered on the 8/2/24, this was delivered virtually but little time was devoted to this in the team's call. This training happened near the end of the pilot and



Outcome Evaluation

Alongside examining the processes related to setting up a new pathway, it is important to examine outcomes in relation to key aims of the new pathway. In this report, we focus on exploring who Kooth's Help to Cope pathway has supported, analysing access and engagement for the referred YP and identifying indicators of the pathway's effectiveness in benefiting these YP.

Who has Kooth's Help to Cope Pathway supported?

How many young people have been referred?

In the 8 month period (mid-July 2023 to end of March 2024), a total of 22 YP were referred from CCETT in Lincolnshire to Kooth's platform through the Help to Cope pathway.

Of YP referred, 4 (18%) were removed from the digital pathway - 3 (14%) YP escalated in their clinical risk level prior to receiving support from Kooth and so were accepted back to CCETT and discharged from Kooth's pathway, and 1 (4%) no longer needed the intervention and was discharged without re-referral. 18 (82%) of the referrals received remained eligible for the pathway and were offered support.

Kooth's Help to Cope pathway enabled YP with choice in how to engage and provided a great level of flexibility, as highlighted in Figure 5 below. Of those eligible, 14 (78%) engaged with the support offered on the Kooth platform. 7 (50%) YP in this category, engaged with both the chat intervention and the non-chat elements of the pathway, to different levels. Of these, 5 (36%) fully completed the chat intervention and 2 (14%) partially completed the chat intervention. All of these users had access to the non-chat elements of the pathway, and made use of the elements according to their personal needs. The remaining 7 (50%) YP in this category engaged solely with the non-chat



elements of the pathway. In considering different elements of the pathway, the data suggests that 5 (36%) YP engaged with asynchronous therapeutic messaging and 6 (43%) engaged with the 'keeping well' self-directed tools, including setting goals, journaling, accessing articles and using the forum.

4 (22%) YP of those eligible did not engage with the Kooth platform. Of these, 2 (50%) were discharged from Kooth and CCETT, with no representation to date, and 2 (50%) presented to CORE CAMHS. The engagement pathway for this IDP is visually presented in Figure 5, below.



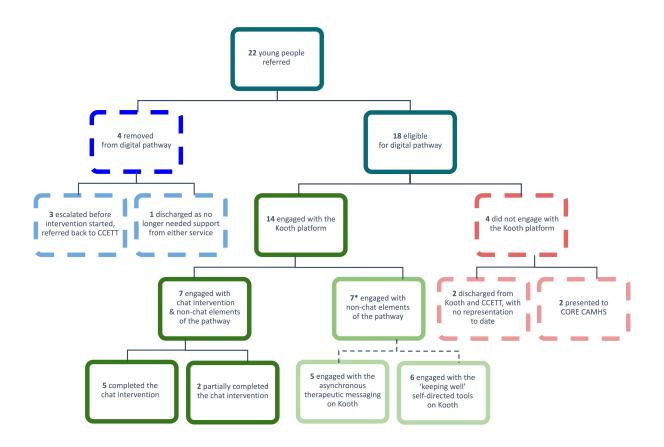


Figure 5: A flow diagram of referred YP and their outcomes.

Referral period July 2023 - March 2024

*Of the 7 who engaged with non-chat elements of the pathway, users could engage with asynchronous therapeutic messaging and / or with the 'keeping well' self-directed tools.



As an anonymous digital mental health service, the traditional Kooth platform attracts a diverse set of YP to our core pathway. In contrast, the Kooth Help to Cope pathway involved non-anonymous referrals, where Kooth practitioners and clinical staff were able to identify YP. However, on the Kooth community and peer-support elements of the Kooth web platform YP were still anonymous to other users. It is therefore highly important to examine who was accessing this pathway to determine if it was accessible to all who needed it (summary in Table 2 below).

- The majority of referrals received were YP who identified as Female (77%) and British (91%).
- The age range of YP referred was 12-18 years (inclusive) from July 2023 to March 2024.
- Each of the following locations represented 5-13% of all referrals: Bourne, Grantham, Lincoln, Peterborough, Skegness, Spalding, and Stamford.

As part of the referral process, YP were given the option to disclose any additional vulnerabilities.

- 45% of YP referred declared vulnerabilities. These included neurodevelopmental conditions, physical health conditions and social vulnerabilities.
- 7 YP shared that they were young carers this represented 32% of all referrals made to this pathway.



Table 2: Demographic data of the 22 YP referred to the Kooth platform through the Help to Cope Pathway

	Frequency	%			
Age					
12	3	13.6%			
13	4	18.2%			
14	2	9.1%			
15	5	22.7%			
16	6	27.3%			
17	2	9.1%			
Gender Identity					
Female	17	77.3%			
Male	3	13.6%			
Other / Not disclosed ²	2	9%			
Ethnicity					
British	20	91%			
Other / Not disclosed ³	2	9%			
Additional vulnerabilities disclosed					
Yes	10	45%			
No	12	55%			

*Referral period: July 2023 - March 2024.

³ This group included 'White and Black Caribbean' and has been sensitively grouped to preserve anonymity of participants. The following options were available for YP to select: Asian or Asian British (subcategories: Bangladeshi, Chinese, Indian, Pakistani, Any other background), Black or Black British (subcategories: African, Caribbean, Any other background), White (subcategories: British, Irish, Any other background), Mixed (subcategories: White and Asian, White and Black African, White and Black Caribbean, Any other background), Any other ethnic group, or I'd rather not say.



² This group included 'Not disclosed' and 'Non-binary' options and has been sensitively grouped to preserve anonymity of participants. The following options were available for YP to select: Male, Female, Non-binary, Prefer not to say, Other (self-disclosed free-text option).

Even though there was still a small number of referrals due to the short duration of the pilot study, this table demonstrates an acceptable range of YP accessing the service, with a similar distribution to Kooth's core pathway engagement. Through the new referral process into this pathway, additional information about vulnerabilities and young carer status was collected and it was identified that there was a large proportion of the YP disclosing these vulnerabilities. This is interesting as it may relate to the digital and flexible nature of the Kooth Help to Cope pathway, and how this provided a flexible yet suitable and acceptable support route for YP with additional needs.



Understanding young carer engagement:

<mark>32%</mark>

of the 22 referrals made to our service were identified as young carers through the referral assessment process. This robust representation reflects that young carers have been identified as having poorer mental-health outcomes than their non-care giving peers (<u>Lacey et al.</u>, <u>2022</u>).

Of the young carers referred to this pathway, 1 (10%) was removed from the digital pathway and was discharged back to CCETT due to high risk presentation. This percentage aligned with the rate of referrals that were 'removed from digital pathway' for the overall pathway (18%), and demonstrated that the Help to Cope pathway was *as* acceptable for this vulnerable sub-population of Lincolnshire-based young carers, as for the wider group of YP experiencing mental health crisis in the contracted area.

Of the young carers referred to our service who were eligible for support through the Help to Cope pathway, 4 (66%) engaged with non-chat elements of the pathway. This reflects a slightly higher rate of non-engagement with the chat intervention among young carers when compared with the group of eligible YP as a whole (41%). Whilst research exploring engagement rates of young carers with mental health support is limited, a recent systematic review highlighted the experience of young carers deprioritising their own mental health support needs - this may be an active choice stemming from feelings of shame or in order to maintain their role as a resilient care-giver (<u>Saragosa et al., 2022</u>).

Of the 6 young carers referred to our service who were eligible for support through this pathway:

- All 6 engaged with the chat intervention and non-chat elements of the pathway.
- $\circ~$ 2 (33%) completed the chat intervention.



- 1 (17%) completed 5 chat sessions and proceeded to request referral to face-to-face services as this YP was now being more ready for additional support.
- 3 (50%) partially engaged with the chat intervention and non-chat elements of the pathway.

The rate of partial engagement in this young carer group, i.e. not completing the chat intervention, was slightly higher than in the eligible YP group. Young carers face time restrictions due to the nature of their role in their household, which may lead to a more passive de-prioritisation of their mental health support needs - they may not have time to engage with structured support. An alternative, or coexisting, explanation may be that 'keeping well' activities were prioritised due to the value a young carer experiencing mental health crises places on peer support - a means of coping that is often described as inaccessible to young carers face-to-face but is **made accessible by digital environments such as Kooth** (Addo et al., 2024).

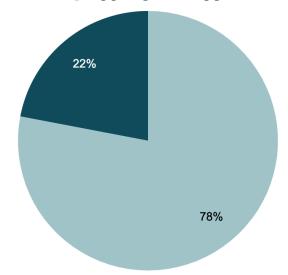
Kooth endeavoured to continue to try to gather feedback from these YP, as well as the broader pathway users, as to evaluate specific barriers to engagement with Help to Cope, their preferred engagement pathways and how Kooth can best support them through our Help to Cope pathway alongside our core service. See '<u>Voice of YP</u>'.



Focus on: engagement with support

How was the engagement with our Help to Cope pathway offer?

- 78% of accepted referrals engaged with the Kooth platform through the Help to Cope pathway.
- An average engagement rate of 79% was reported within a systematic review of digital mental health interventions for YP, with a wide range of 16%-100% reported across all studies included (Liverpool et al., 2020).
- Comparing with CCETT engagement figures we observed a



Engaged Did not engage

similar 'did not engage' rate with CCETT reporting approximately 24% of referrals having either 1 assessment (14%) with them or did not engage at all (10%). This data aids in contextualising Kooth's pilot engagement data. Improvements can be made to reduce 'did not engage' rates, which is discussed in the recommendations section.



How has Kooth's Help to Cope pathway addressed barriers to discharge from CCETT?

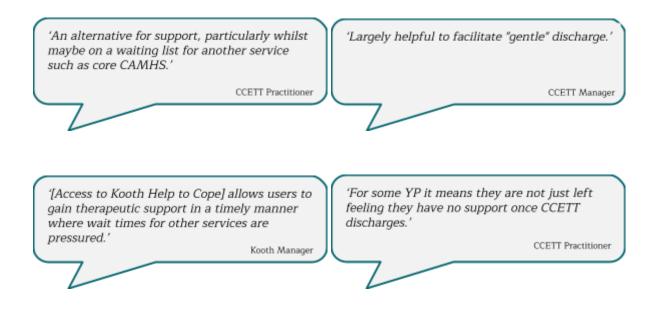
Waiting lists for ongoing or longer-term support presented a barrier to discharge from crisis services. YP may be reluctant to reach out independently to other services and repeat their experience.

YP may feel concerned that they will be left without support following discharge.

This created barriers to discharging YP from CCETT.

Figure 6: Representing barriers to discharging YP from CCETT as identified by CCETT staff in mid-point surveys

Feedback from all staff groups involved in the pilot support the utility of the Kooth Help to Cope pathway -





What has been the impact of referral process challenges on engagement?

Delays and difficulties with YP creating an account and the referral being received by Kooth contribute to the non-engagement rate:

'Some YP that haven't engaged did have delays/difficulties in the signing up process which could have contributed to not engaging.' Kooth Practitioner 'It seems that YP's who are referred and where there is no delay i.e. on occasions we can see YP's have signed up but have not received a referral or they have signed up to the wrong pathway - this delay and back and forth seems to create a barrier to engagement. Where referrals are received and YP's have signed up in a shorter time frame - the engagement is far more likely.' Kooth Manager

Service data suggested that all YP who did not engage, created an account but then did not log in to the platform again following this action. It appears that these YP did not have the opportunity to view messages sent to them by practitioners, as they were sent within the platform and there is no notification external to the platform.

This barrier to initial engagement had been highlighted by Kooth practitioners, who note that once YP have engaged with an initial chat, they tended to continue to engage positively with support offered.

'Once we have had a fi has been really positive get the initial engagem	e but can be tricky to
	Kooth Practitioner



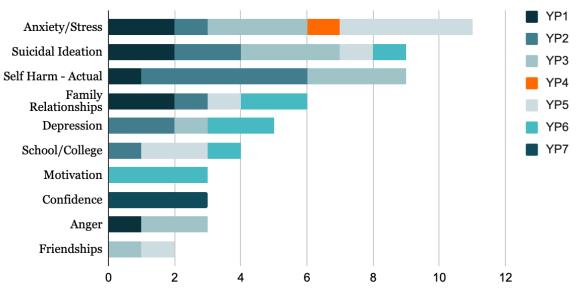
Actions were being taken by Kooth to support improvements to the referral process (see <u>Table 1</u>).

Focus on: outcomes of support

How did children and young people in crisis benefit from the support offered by Kooth's Help to Cope Pathway?

Kooth's Help to Cope pathway offers YP support around a diverse range of presenting issues - 26 distinct presenting issues were identified in chats.¹

Presenting issues were logged within chats with practitioners, where YP could freely express their concerns. Anxiety or stress was the most common presenting issue, followed by suicidal ideation and self-harm (actual).



Top 10 Presenting Issues

Frequency of Presenting Issues Identified

Figure 7: The 10 most frequently identified presenting issues for YP who attended chat sessions *Referral period July 2023 - March 2024. Data from 7 YP.

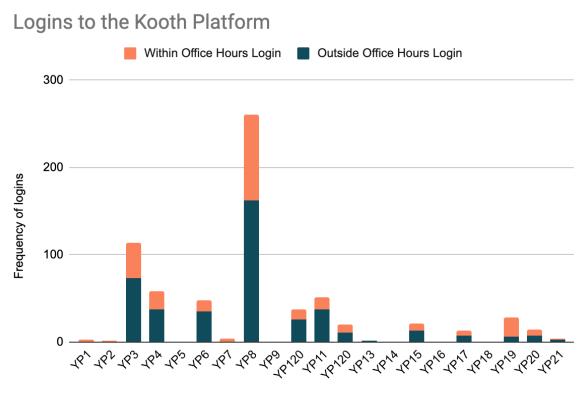


Kooth's online environment promotes disinhibition by providing an open and safe space for YP to discuss concerns that they may be embarrassed to disclose in face-to-face settings (Prescott et al., 2019).

¹ Other Presenting Issues identified included; Alcohol, Attachment, Bereavement, Body Image, Boyfriend/Girlfriend, Bullying, Confidence, Domestic Violence (parent/family), Mood Swings, Sadness, Self-worth, Self-harm (thoughts), Sleep difficulties, Trauma, Trust Issues and Violence.

Kooth's Help to Cope pathway offered flexibility and autonomy in its support

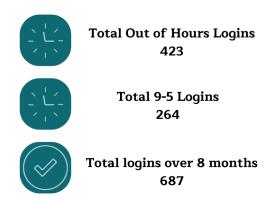
- the data showed that the platform was utilised by YP both within and outside traditional working hours (9am-5pm).



Young people referred to Kooth Help to Cope

Figure 8: Frequency of logins within/outside office hours. *Referral period July 2023 - March 2024.





Login data demonstrated the access patterns of YP engaging with the Kooth platform. On average, YP logged in out-of-hours 20 times (SD = 37.6, R = 162), compared to 13 logins during usual work hours (SD = 22.2, R = 99).¹ 55% of YP were more likely to login out-of-hours.

SD = *standard deviation, R* = *range*

¹ Averages for login data were affected by two outliers who logged in significantly more than others.

Overall, most YP frequently accessed Kooth once they created their logins, and many continued to do so after completing the structured intervention pathway, utilising 'keeping well' and safety planning support.

YP engaged in the pathway at their own pace, wherever they felt comfortable, or when they needed support, and importantly without delay - whether that was during within or out-of-hours. YP took an active role in 'keeping well' by engaging in helpful resources, such as mini activities alongside chats and messaging support (Dhesi et al., 2021). Kooth's Help to Cope pathway provided increased autonomy and continuous care to ensure feelings of safety and support at all stages of the pathway.

Kooth's Help to Cope pathway offered unparalleled community support

- YP shared advice, socialised, and learned from others' experiences within the safe, supportive and positive community space at Kooth.

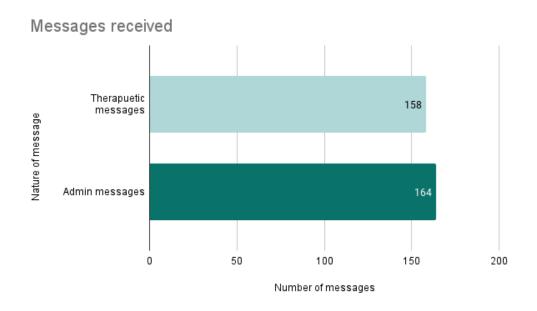
Articles and forums were viewed by YP 81 times in total. YP viewed forums related to their presenting issues or goals e.g. suicidal ideation or emotional exploration related articles and discussion boards. They also viewed guides to using Kooth e.g. on goal setting and getting support.

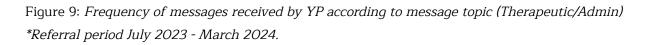


Peer content aids in reducing loneliness by allowing them to relate and empathise with others facing similar issues <u>(Stevens et al., 2021)</u>. In the Help to Cope pathway, it provided a source of comfort and relief from distress that may not have been available offline. Feeling connected promotes empowerment, which motivates individuals to work towards their goals i.e., to make progress towards meaningful change. All content on Kooth is pre-moderated and safeguarded to ensure it is a continuously safe environment for all.

Asynchronous messaging played a key role in sustaining engagement alongside supporting YP

- the data suggested that YP who received a lot of messages attended more chats and engaged with their goals more.





To further promote sustained engagement, the Help to Cope pathway incorporated asynchronous messaging, which is a way to reach out to YP to prompt continued interaction with the support system and also provide support between synchronous chats.



A total of 322 messages (M = 7 messages, SD = 9.4) were sent out to YP who engaged through asynchronous messaging. Of those 322 messages, 158 were therapeutic in nature (M = 7 messages, SD = 9.2) and 164 were admin messages (M = 8 messages, SD = 9.8) e.g., rating chats, welcoming to site, and technical issues. All these messages had value towards the pathway as they promoted encouragement and engagement for YP. This proactive approach not only kept YP connected but also reinforced the availability and relevance of the pathway, fostering a sense of ongoing support. Communication contributes to a comprehensive support network, further enhancing the depth of engagement with the Help to Cope Pathway.

The Help to Cope Pathway facilitated access to support for vulnerable YP by extending chat support services beyond traditional working hours (9am-5pm)

- ensuring timely assistance for YP when crises occurred outside standard support service timeframes.



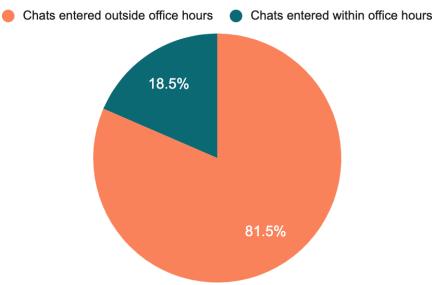


Figure 10: Chat attendance rates according to time frames (inside or outside 9am-5pm) **Referral period July 2023 - March 2024.*



Examining key results reveals active and diverse engagement, with 66 booked chats⁴ indicating a substantial use of real-time support. Notably, 82% (22) of successful chats occurred outside office hours, emphasising a strong demand for assistance beyond standard hours. The pathway effectively addressed immediate needs during traditional office hours, with 8% (5) chats occuring at this time, while only 6% (4) chats were booked during this period where YP did not enter/attend. The choice and flexibility around chat times provided YP with a personalised programme of support catered around their needs. Improving the likelihood of attending chats in an intervention increases likelihood of intended outcomes. Meaningful improvement in goals, for example, is positively correlated with chat time (Jacob et al., 2020). This makes chats with a practitioner easier to attend and more suitable for YP lifestyles, and may have increased YP's likelihood of attaining goals.

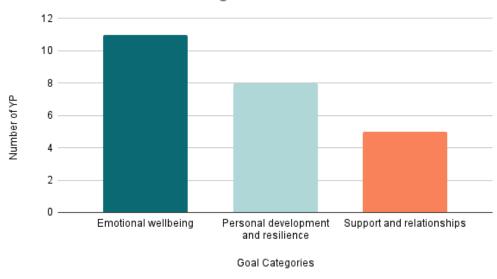
YP engaged with goal-setting on Kooth's Help to Cope pathway and achieved meaningful positive change in their goals.

During chat sessions, YP worked together with practitioners to set realistic and achievable goals. These goals can be self-set or set by practitioners based on behaviour or issues voiced by YP during sessions. The active utilisation of goal-setting in Help to Cope is apparent. In total, 32 goals were set by the practitioner for YP. Of these, 47% (15) were updated, meaning that they were engaged with after being set. Of the updated and engaged goals, all (100%) achieved meaningful change. Each YP who engaged with their goals attained an average goal movement of 9 points (out of a possible maximum 10 point movement). This movement is very positive with a '3 point' movement considered to constitute a meaningful change (Jacob et al., 2020). Among users who successfully completed all of their goals, a total of 8 goals were achieved (by

⁴ Out of all booked chats, YP did not attend 5 within office hours compared to 35 chats outside office hours.



3 YP). This not only reflects iterative progress but also emphasises the adaptability of the pathway in addressing the evolving needs of its users. Within the goal setting process, YP were presented with a choice of goal categories to work on, together with the practitioner, to help set their goals. This is illustrated in Figure 11 below, where goal categories have been sorted into common themes. Within the theme 'emotional wellbeing', emotional exploration was the most commonly set goal category for YP, and was frequently addressed by practitioners to facilitate personal growth (Jacob et.al, 2020).



Number of YP vs Goal Categories

Figure 11: Goal categories selected by YP referred to the Help to Cope pathway (sorted into themes).

*Referral period July 2023 - March 2024.

Opportunities for significant positive change lie in collaborative goal-setting, which allowed YP to define goals for mental health and well-being with practitioner assistance. This approach has been employed across CAMHS services in the UK and is validated by research findings from <u>Edbrooke-Childs et al. (2015)</u> and <u>Jacob et al. (2015)</u>, showcasing its effectiveness in capturing relevant and meaningful change.



Retention to an online counselling service can be linked to goal use - more engagement with associated activities in the service including time overall and chat time contribute to more meaningful improvement. Those who see early improvements in goals may be more likely to engage with services (Jacob et al., 2020).

YP are supported to create and utilise personalised safety and wellbeing plans in line with <u>NICE quidance</u>

- Our data demonstrated that 2 YP who completed their chat interventions accessed their safety plan and Kooth's crisis support information pages on multiple occasions throughout their intervention.

The development of structured and personalised information for YP is a key part of ensuring that they remain informed about their options of support. Kooth's Help to Cope pathway highlights the importance of safeguarding and collaboration with YP in order to provide care that is tailored to their individual needs.

Clinical outcomes

There were trends towards improved quality of life $(EQ-5D-Y)^5$ over the 6 sessions in YP who complete the pathway - but we were tentative to statistically analyse this data yet as the sample sizes are very small.

⁵ The EQ-5D-Y Quality of Life measure <u>(Kreimeier & Greiner, 2019)</u>, youth version for children and adolescents. Completed by YP in the first and last chat session.



Championing the voice of the young person

At Kooth we highly value the voice of YP in shaping our services for continuous improvement.

A core pathway Kooth service user survey revealed that **98% of YP emphasised the importance of having the autonomy to choose what they did on Kooth** (Salhi et al., 2023). This empowerment allows YP to determine **when** and **how** they receive support, therefore fostering a user-centred experience which effectively contributes to their mental wellbeing. Through routinely approaching YP for feedback, we have recognised the importance in making sure the voice of the YP is heard.

As part of our commitment to ensuring the active involvement of YP, we adopted a similar approach with the Help to Cope pathway, actively seeking their opinions on the pathway's efficacy as follows:

- Using emails and texts, we reached out to YP meeting specific criteria (ages 11-18 (and up to 25 for young carers), referral to Kooth by CAMHS services via the IDP, and consent for contact).
- These criteria were collaboratively established with our internal safeguarding and clinical teams, CCETT and the LCC commissioner.
- Our inclusive approach to survey design involved engaging YP at all levels, tailoring questions based on their level of engagement.

The overarching aim was to understand each YP's experience with the Help to Cope pathway, ultimately enhancing these services for all YP. Despite our proactive efforts, we did not receive responses through this initial feedback method, possibly due to challenges surrounding engagement. We explore this further in the Recommendations Section below.

Ultimately, this approach highlighted our ongoing commitment to gathering comprehensive feedback and refining our services.



End Of Session Questionnaire

At the end of each chat session, YP were offered the opportunity to give feedback on how they felt about the chat, by completing a short End of Session (EOS) questionnaire.

Of all completed EOS received by YP who have completed their intervention:

• **100%** indicated that YP felt heard, understood and respected in their chat ("a lot")

• **83%** indicated that what they had talked about in that chat was important to them ("a lot")

- **100%** indicated that they felt the practitioner helping them was a good fit for them ("a lot")
- **83%** indicated that the session had felt right for that YP at that time ("a lot")
- **75%** of YP indicated that they would recommend Kooth to a friend

This feedback highlighted the value in Kooth's Help to Cope structured chat interventions, and demonstrated the skill of our highly-trained practitioners in ensuring YP felt **heard**, **understood**, **and supported** in chat.



Insights from a Case Study

This is a story about a young woman, whom we will refer to as 'Stacy'. As a new college student, Stacy found herself at a crossroads in life. Struggling with low mood, a sense of hopelessness, and a recent suicide attempt, she was desperately seeking happiness and a way to regain control over her life. With the help of a seamless referral process from CCETT to Kooth and the support of Kooth's Help to Cope pathway, Stacy was able to transform her life.

Stacy's path to recovery started with the important referral to CCETT by a vigilant first responder who recognized her need for support following a suicide attempt. Within a swift 72-hour referral by CCETT and a 24-hour response time to the referral, Kooth engaged with Stacy. During the initial assessment, it was identified that Stacy's risk level hovered in the amber zone, primarily attributed to a suicide attempt occurring more six weeks prior. Kooth promptly extended **structured support** through six structured sessions and **messaging assistance**.

Throughout these sessions, the focus centred on fostering Stacy's resilience and self-understanding. Collaboratively, the Kooth practitioner and Stacy worked towards establishing a daily routine, unravelling the complexities of her emotions, and strengthening her relationship with her mum. As the six-week journey unfolded, Stacy's transformation was evident; she was having open chats and going on social outings with her mum. Her mum helped her establish a daily routine, and Stacy felt confident to work on new friendships at college. At the close of her six sessions her risk was at the lowest level.

When asked to provide feedback, Stacy expressed **feeling genuinely heard and respected**. She wholeheartedly endorsed Kooth, noting she would recommend the service to others. She conveyed that the sessions were just right for her and the topics discussed were important for her journey.



Stacy's success story highlights the effectiveness of the **referral process** when it occurs within 72 hours and Kooth meets with the young person within 24 hours. This rapid response is essential, especially for higher-risk youth, ensuring that they can access help promptly.

In a **brief interview** with the Service Manager, Ryan, he noted that as shown in this case story, a critical aspect of Kooth's Help to Cope pathway success was its **flexibility**. Young people could register for Kooth's digital mental health services while the referral process was in progress, ensuring that they could begin benefiting from the support immediately, not being delayed by paperwork or waitlists. This approach minimised potential delays in accessing care.

Furthermore, Ryan shared that an important aspect that made the Help to Cope pathway pilot successful was the use of **multidisciplinary team meetings**, such as transfer event weekly meetings, allowing for effective communication and **collaboration with CCETT**. This ensured that young people like Stacy received the most appropriate level of care, **tailored** to their unique needs and circumstances. It also provided an opportunity to connect a young person to a different level of care if the team deemed appropriate.

Stacy's journey to healing serves as a powerful testament to the impact of timely and flexible digital mental health support. With the right resources and support, young people like Stacy can find their path to recovery, rediscover happiness, and rebuild their lives. Stacy's story is a beacon of hope, illuminating the potential for **positive change**.



Recommendations

Development of the Help to Cope Integrated Digital Care Pathway in Lincolnshire has allowed a wealth of learning, with opportunities to improve the impact of this specific service and inform service redesign and innovation projects across Lincolnshire and the NHS more generally.

There are some strong positives of the pilot:

- Although the service was developed and launched rapidly, close co-production between teams has ensured that referrers have trust in the service model, with the potential identified to significantly reduce pressure on CCETT and thereby release capacity and improve staff morale.
- Once YP were engaging with chats, adherence was good, and the service generated positive outcomes for YP.

Areas to improve:

However there are some clear areas to improve, particularly in relation to the volume and proportion of accepted referrals. Many of these challenges are not unique to this pathway and reflect the inherent challenges of introducing innovative models of care and adoption of technology in the NHS, with common issues related to interoperability, technical integration, and building trust across teams.

The recommendations from the pilot findings relate heavily to the process part of this report. Highlighted here are three key stages to implementation that are important to the success of new integrated care pathways: 1) Process mapping and consultation before contract procurement / tenders, 2) Collaboration and consultation between service providers prior to implementation, 3) Removing utilisation barriers and supporting appropriate evaluation.



1) Process mapping and consultation before contract procurement / tenders Before launching the project, commissioners had undertaken work with stakeholders to understand the potential digital solutions available to support CCETT. However, there was relatively little work undertaken with CCETT staff to understand the existing service user journey and requirements to understand user needs, existing referral mechanisms, eligibility criteria and what success for this pathway might look like. Kooth and CCETT teams worked closely together to co-produce process maps and service pathways, but this essential work reduced the time available for service launch and delivery. Key areas to learn from this pilot and recommendations are listed below -

1.1 Process mapping is required before commissioning new care pathways - to determine specific needs and targets alongside potential benefits. This work could be undertaken in collaboration with digital providers and other stakeholders, bringing experience from user experience design and product development to solve specific system problems. This therefore aims to ensure funding allocation is aligned to commissioner and trust needs.

1.2 Short term contracts require new short-term staff, short-term evaluation outcomes and limited time to ramp-up or build trust with service referrers, which creates an array of challenges. Longer term contracts, on the other hand, would be more feasible and would therefore likely lead to more successful implementation and ability to support decision making more effectively due to more complete outcomes and impact. This pilot afforded less than a 4 month period from commissioning to accepting YP into the IDP. This inevitably led to delays due to implementation challenges which called for a well needed extension to the pilot.



2) Collaboration and consultation between service providers prior to implementation

2.1 Implementation resourcing and calculated costs should be included in the budget. Typically, and in this pilot, payment is attached primarily to direct service delivery time, however clinical consultation, development and innovation costs are a high resource for NHS services. Likewise, support from within NHS teams to progress IT interoperability requirements and support the development of data sharing models is essential for timely service launch, but this capacity is often limited.

3) Removing utilisation barriers and supporting appropriate evaluation

3.1 Time and communication is required to build trust from NHS referrers (clinicians and practitioners) - to win over 'hearts and minds'. Kooth has started this by conducting training and having regular virtual and phone communication methods, however as demonstrated here, this takes time and requires a top-down flow of information - but bottom-up buy-in to the new pathways. Specific allocated time is required for training for both services, so that this is not a burden on the referring service. In this pilot, a limited number of training sessions were delivered due to constraints on staff time from CCETT.

3.2 Moving forward, Kooth and CCETT need to tighten up the assessment and referral criteria to ensure that 1) more YP are referred and 2) those who are referred are suitable and therefore can start their 1-1 support (the pilot has shown high success rates following the start of 1-1 support). Working on removing barriers - such as improving the IT referral process, improving trust and referral criteria clarity can support this. Additionally understanding how the Help to Cope pathway supports CCETTs needs - in the earlier needed process mapping, would have improved speed of referrals.



3.3 Support for external evaluations of these new pathways is recommended - Kooth has evaluated this pilot in-house utilising specialist researcher time and other internal staff. Yet, Kooth researchers recognise that this requirement for internal evaluations from service providers is not sustainable, especially for a less mature company to conduct. Evaluation is critical to determine what is working well, what can be improved or avoided in the future. Otherwise, the learning and development from this pilot would not have been utilised and the contract cost would have been wasted. Researchers have been working closely with CCETT and LCC as part of this evaluation, yet data sharing is still challenging, in particular determining success based on engagement rates, pathway completions and outcomes. Not having a benchmark is problematic for determining the context of engagement and disengagement and for the ambition to provide health economic related outcomes of the pathway.



Summary

Kooth's Help to Cope IDP pathway was co-designed to meet the growing demand for crisis step-down support, which in 2O23 saw record highs for YP being referred to crisis teams in CAMHS (<u>NHS Digital, 2O24</u>). The Help to Cope pathway specifically offered personalised chat interventions and 'keeping well' resources alongside crisis prevention strategies and safe crisis management. Its implementation utilised Kooth's existing digital infrastructure, resource capacity and clinical expertise and ongoing partnership between Lincolnshire and Kooth.

This report has demonstrated that joint working processes between Kooth and Lincolnshire CCETT have been highly successful - in particular the utilisation of Integrated Digital Safeguarding Pathway which has met the specification for a safe and appropriate level of crisis support to be provided to all YP referred to the pathway. However, the pilot has highlighted a key challenge in the implementation and integration of this pathway - the referral process, which has presented delays to interventions beginning and may have impacted YP's engagement with the support available. Recommendations and ongoing actions are in place to address this issue going forwards, ranging from training to improve confidence in referrals, tightening up referral criteria and improving referral IT processes.

Nevertheless, Kooth and CCETT have demonstrated value in processes implemented - based on expertise and experience in the digital mental health and risk management space, however recommendations have been made to ensure the expertise and consultation is valued and sustainable within contract costing and budgeting where new care pathways are required to be implemented.



Kooth's Help to Cope pathway has so far enabled a range of YP, including vulnerable groups such as young carers, to engage flexibly with digital support be that through our structured chat interventions or through our impactful

'Those [YP] who I have completed work with have said they found the service useful and given positive feedback on the end of session questionnaires' Kooth Practitioner

7

peer community. YP's feedback suggested a high rate of satisfaction with the chat intervention, and also demonstrated high engagement rates with Kooth outside of their sessions, such as with asynchronous messaging, reading articles or setting and monitoring goals. Kooth's out-of-hours offering for chats or platform engagement was highly popular, with the majority of chats booked and attended being out of traditional working hours.

The feedback I have received [from referred YP] has been positive.' **CCETT** Practitioner

Whilst we strive to gather further feedback from YP on how they have experienced Kooth's Help to Cope service, this evaluation demonstrates

positive outcomes for those that have engaged with the support we have offered. We are excited about the prospect of overcoming current challenges in order to support more YP to step-down from crisis support, while providing YP with choice, flexibility and autonomy in their care and help-seeking journey.



Appendices

Appendix 1: Data Collection Procedure

Service Data

Following the initial signup to the Kooth platform, service data was recorded internally, including;

<u>Platform Interaction</u> - input from YP and their use of the platform: page visits, number of logins, attendance to chats out-of-hours or within working hours, number of chats, goal movement, demographics, journal use, contact with other services

<u>Practitioner Input</u> - information from chats logged by direct staff: presenting issues, collaborative goal setting and goal movement, signposting and safeguarding, case notes, therapeutic messaging

Additional Data - moderator messages and edits, admin messaging

This information enabled the observation of any differences or patterns among those referred in relation to engagement pathways, while considering their personal characteristics.

Measures

Outcome measures were used beyond initial assessments to monitor the progress of YP as they attended chat sessions. This includes routine outcome measures, initial clinical outcome measures and final session outcome measures. Outcome measures mentioned in this report;

- EQ-5D-Y, a child-friendly quality of life measure
- End of Session (EOS) questionnaire, a measure of YP satisfaction with chat sessions



Practitioner surveys

Staff surveys were designed to understand the impact of the integration between services, and the effectiveness of the collaboration in providing stepdown crisis care. Three types of questions were primarily used in each questionnaire;

- Rating scales on significance, success (of the integration) and impact
- Likert scales on satisfaction and appropriateness (of referrals)
- Free text questions on communication, confidence in the process, challenges/limitations and benefits of the pathway structure

Overall, there were 2 responses from Kooth Direct staff, 4 responses from Non-Direct staff, 1 response from a CCETT Manager and 5 responses from CCETT Practitioners. All staff were supported to complete the surveys during work hours and reimbursed for their time, upon completion, with a £5 Amazon voucher.

Appendix 2: List of Figures

Figure 1: Types of support offered through Kooth's Help to Cope pathway.

Figure 2: A flow diagram of Kooth's Help to Cope Safeguarding escalation pathway.

Figure 3: Example of our safeguarding process in action - Case Study D.

Figure 4: Schematic of the referral pathway from CCETT to Kooth's Help to Cope as part of Kooth's Integrated Digital Pathway

Figure 5: A flow diagram of referred YP and their outcomes

Figure 6: Representing barriers to discharging YP from CCETT as identified by CCETT staff in mid-point surveys

Figure 7: The 10 most frequently identified presenting issues for YP who attended chat sessions

Figure 8: Frequency of logins within/outside office hours.



Figure 9: Frequency of messages received by YP according to message topic (Therapeutic/Admin)

Figure 10: Chat attendance rates according to time frames (inside or outside 9am-5pm)

Figure 11: Goal categories selected by YP referred to the Help to Cope pathway (sorted into themes)

Appendix 3: List of Tables

Table 1: Key challenges, improvements made and actions taken in relation to referral-pathway related issues - results of a thematic analysis of weekly meeting logs, mid-point interview responses and referral data.

Table 2: Demographic data of the 22 YP referred to Kooth Help to Cope Pathway

Appendix 4: Abbreviation List

YP - Young Person / People

CAMHS - Child and Adolescent Mental Health Services

NHS - National Health Service

CCETT - CAMHS Crisis and Enhanced Treatment Team

SD - Service Delivery

IDP - Integrated Digital Pathway

IT - Information Technology

SG - Safeguarding

LCC - Lincolnshire County Council

LPFT - Lincolnshire Partnership Foundation Trust

KPI - Key Performance Indicator

SD - Standard Deviation

R - Range



M - Mean

EQ-5D-Y - The Euro Quality Of Life Measure - 5 dimension questionnaire (youth version)

EOS - End of Session

BHS - Beck Hopelessness Scale



References

- Addo, I. Y., Aguilar, S., Judd-Lam, S., Hofstaetter, L., & Poon, A. W. C. (2024). Young carers in Australia: understanding experiences of caring and support-seeking behaviour. Australian Social Work, 77(1), 60-73. <u>https://doi.org/10.1080/0312407X.2021.1971271</u>
- Da'Bell, D. (2022). *Digital Safeguarding and Risk*. In H. Wilson (Ed.), Digital Delivery of Mental Health Therapies (Pp. 48-60); Jessica Kingsley Publishers.
- Dhesi, M., Sefi, A., Donati, M., Hayes, J., & Cooper, M. (2021). Helpful and unhelpful elements of synchronous text-based therapy: A thematic analysis. *Counselling and Psychotherapy Research, 22(1)*, 157-165. <u>https://doi.org/10.1002/capr.12414</u>
- Dutton, B., Humphrey, N., & Qualter, P. (2023). Getting the pieces to fit: NHS and third sector collaboration to enhance crisis mental health service provision for young people. *BMC Health Services Research*, *23*(1), 1-11. <u>https://doi.org/10.1186/s12913-023-09198-w</u>
- Edbrooke-Childs, J., Jacob, J., Law, D., Deighton, J., & Wolpert, M. (2015). Interpreting standardized and idiographic outcome measures in CAMHS: what does change mean and how does it relate to functioning and experience? *Child and Adolescent Mental Health, 20*(3), 142–148. <u>https://doi.org/10.1111/camh.12107</u>
- Edwards, D., Carrier, J., Csontos, J., Evans, N., Elliott, M., Gillen, E., Hannigan, B., Lane, R., & Williams, L. (2023). Review: Crisis responses for children and young people a systematic review of effectiveness, experiences and service organisation (CAMH-Crisis). *Child and Adolescent Mental Health*, *29*(1). <u>https://doi.org/10.1111/camh.12639</u>
- Jacob, J., Costa da Silva, L., Sefi, A., & Edbrooke–Childs, J. (2020). Online counselling and goal achievement: Exploring meaningful change and the types of goals progressed by young people. *Counselling and Psychotherapy Research*, 21(3). https://doi.org/10.1002/capr.12363
- Jacob, J., Edbrooke-Childs, J., Law, D., & Wolpert, M. (2015). Measuring what matters to patients: Using goal content to inform measure choice and development. *Clinical Child Psychology and Psychiatry*, *22*(2), 170–186. <u>https://doi.org/10.1177/1359104515615642</u>
- Kreimeier, S., & Greiner, W. (2019). EQ-5D-Y as a Health-Related Quality of Life Instrument for Children and Adolescents: The Instrument's Characteristics, Development, Current Use, and Challenges of Developing Its Value Set. *Value in Health*, *22*(1), 31–37. <u>https://doi.org/10.1016/j.jval.2018.11.001</u>
- Lacey, R. E., Xue, B., & McMunn, A. (2022). The mental and physical health of young carers: A systematic review. *The Lancet Public Health*, 7(9), e787-e796.
- Liverpool, S., Mota, C. P., Sales, C. M. D., Čuš, A., Carletto, S., Hancheva, C., Sousa, S., Cerón, S. C., Moreno-Peral, P., Pietrabissa, G., Moltrecht, B., Ulberg, R., Ferreira, N., & Edbrooke-Childs, J. (2020). Engaging Children and Young People in Digital Mental Health Interventions:



Systematic Review of Modes of Delivery, Facilitators, and Barriers. *Journal of Medical Internet Research*, *22*(6), 1–17. <u>https://doi.org/10.2196/16317</u>

Mind. (2010). An independent inquiry into acute and crisis mental healthcare Listening to experience. Mind.

https://www.mind.org.uk/media-a/4377/listening_to_experience_web.pdf

NHS Digital. (2024). Mental Health Services Monthly Statistics, Performance November 2023. NHS Digital. <u>https://digital.nhs.uk/data-and-information/publications/statistical/mental-hea</u>lth-services-

<u>monthly-statistics/performance-november-2023</u>

- Prescott, J., Hanley, T., & Ujhelyi Gomez, K. (2019). Why do young people use online forums for mental health and emotional support? Benefits and challenges. *British Journal of Guidance* & Counselling, 47(3), 317–327. <u>https://doi.org/10.1080/03069885.2019.1619169</u>
- Rhodes, B. (2018). Multiagency Review Of Mental Health Crisis Services In Lincolnshire Executive Summary. Lincolnshire Multiagency Steering Group. <u>https://lincolnshire.moderngov.co.uk/documents/s23875/Appendix%20A%20-%20Review%</u> <u>20of%20Mental%20Health%20Crisis%20Services%20Executive%20Summary.pdf</u>
- Salhi, L., Cowling, M., Howard, E., Johal, K., Rooney, A., Bernard, A., Salter-Hewitt, T., Hassan, Y., Kleeman, T., Ryland, K., & Rock, B. (2023). *Giving Young People a Voice to Inform Digital Services.* Kooth PLC.

https://20406436.fs1.hubspotusercontent-na1.net/hubfs/20406436/Hosted/Kooth_Giving %20Young%20People%20a%20Voice%20to%20Inform%20Digital%20Services.pdf

- Saragosa, M., Frew, M., Hahn-Goldberg, S., Orchanian-Cheff, A., Abrams, H., & Okrainec, K. (2022). The Young Carers' Journey: A Systematic Review and Meta Ethnography. *International Journal of Environmental Research and Public Health*, 19(10), 5826. <u>https://doi.org/10.3390%2Fijerph19105826</u>
- Stevens, M., D'amico, F., Cartagena-Farias, J., Mindel, C., Sefi, A., & Evans-Lacko, S. (2021). *May* 2021 Findings from the Kooth evaluation CARE POLICY AND EVALUATION CENTRE CPEC CPEC Report. https://www.lse.ac.uk/cpec/assets/documents/koothevaluation.pdf
- Stevens, M., Farías, J. C., Mindel, C., D'Amico, F., & Evans-Lacko, S. (2022). Pilot evaluation to assess the effectiveness of youth peer community support via the Kooth online mental wellbeing website. *BMC Public Health*, 22(1). <u>https://doi.org/10.1186/s12889-022-14223-4</u>
- Unsworth, H., Dillon, B., Collinson, L., Powell, H., Salmon, M., Oladapo, T., Ayiku, L., Shield, G., Holden, J., Patel, N., Campbell, M., Greaves, F., Joshi, I., Powell, J., & Tonnel, A. (2021). The NICE Evidence Standards Framework for digital health and care technologies – Developing and maintaining an innovative evidence framework with global impact. *DIGITAL HEALTH*, 7, 205520762110186. <u>https://doi.org/10.1177/20552076211018617</u>
- Vusio, F., Thompson, A., Birchwood, M., & Clarke, L. (2019). Experiences and satisfaction of children, young people and their parents with alternative mental health models to inpatient settings: a systematic review. *European Child & Adolescent Psychiatry*, 29(12), 1621–1633. <u>https://doi.org/10.1007/s00787-019-01420-7</u>



Wolpert, M., Harris, R., Hodges, S., Fuggle, P., James, R., Wiener, A., Mckenna, C., Law, D., York,
 A., Jones, M., Fonagy, P., Fleming, I., Munk, S., Payne, C., & Perry, E. (2019). *THRIVE Framework for System Change*. CAMHS Press.
 <u>https://implementingthrive.org/wp-content/uploads/2019/03/THRIVE-Framework-for-syste</u>
 <u>m-change-2019.pdf</u>



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Author Affiliations and Conflict of Interest

Researchers evaluating this pilot are researchers or staff employed and receive honorarium by Kooth plc. The funder remained independent and did not influence the design or outcome of the study. Evaluation proposals were reviewed by CCETT and LCC. Dr Louisa Salhi, the PI, also holds an honorary research position at the University of Kent, UK, remaining a researcher in the field of mental health and cognitive psychology.

Acknowledgments

The authors would like to acknowledge significant contributions from both CCETT and Kooth staff, as well as LCC commissioners. In particular we acknowledge Sophie Weaver, Liz Bailey, Ryan Bird and Kate Elliott from Kooth plc for their contributions to the information relating to service delivery of the pilot and safeguarding procedures. We would also like to thank Kal Johal & Olivia Hind for contributing to the report by providing commissioning and NHS-specific knowledge. We would like to acknowledge the CCETT and Kooth practitioners for providing insights via the surveys and discussions held over the pilot, along with the managers from CCETT; Emma Houltby and Anna Spencer who provided valuable service data insights and specialised knowledge. The LCC commissioners Emily Humphries and Lydia Whitton also provided feedback, guidance and data where possible.





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