

## Giving Young People a Voice to Inform Digital Services.

How Kooth is responding to feedback and remaining at the forefront of innovation in digital mental health.



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"I think [Kooth is] very good. Especially if you are a young child experiencing feelings that you may be confused about. You don't need referrals to access this. Nobody had to know, and it's anonymous. It's a great way of getting your feelings out there and getting the support you need right away for free, before it progressively gets worse."

Kooth User

"As someone who is experiencing mental health issues as well as being neurodivergent, it's really great to have someone external from all my problems to talk to; they have no judgement, and it is a safe place. It is a great way to feel listened too without having two talk to someone who already knows you."

**Kooth User** 

### **Foreward**

Significant strides have been made in the provision and use of digital mental health tools and services for children and young people. Kooth has been leading developments and innovation since the early 2000s. Over this time, the extent to which digital is a pervasive part of young people's lives has been an enabler for accessing help. Young people's perspectives and choices regarding multiple digital mental health-related topics are influenced by the digital ecosystem in which they are embedded. This correlates with a rise in the acceptability of digital mental health platforms, like Kooth, among young people. This comes with a responsibility from providers to ensure that risk and safeguarding are paramount. At Kooth, the safety of our users is front and centre in our efforts to support young people in making positive choices about their mental health and wellbeing.

This report will necessarily be read with two important contextual factors: First, the rising acuity and prevalence of mental health difficulties and challenges for children and young people. Of course, this has been exacerbated by Covid but cannot be fully explained by Covid. Second, the sustained pressure and demand on the capacity in the system to respond quickly and effectively to young people needing help with their mental health. This is not only in the National Health Service, but in schools, colleges, universities and local authorities across the country.

Reading this report will be cause for optimism, too. It sets out how engaged children and young people are in their own mental health journeys. There is greater awareness of the importance of good mental health. At Kooth, we are delighted that so many of our users want to share their experiences to help us improve what we do on their behalf. We too are on a journey to deliver the most personalised mental healthcare possible. This report provides an opportunity to reflect on the past year, learn and celebrate. But the journey continues and the pace of progress and the outcomes will only be fully achieved by hearing the voice of users, loud and clear.

So, in the year ahead, our commitment is to do more to understand the needs of current and potential users, especially from seldom-heard groups. If we have learned anything from the recent period, it is that we cannot be complacent. The degree to which health inequalities persist and grow is not acceptable.

The launch of this report coincides with the redoubling of Kooth's efforts and commitment to understand and engage with children and young people to continue to provide personal care and support people on their journeys.



**Brian Rock**Clinical Director

### **Executive Summary**

This report provides a timely look at Kooth, bridging insights from young people, from professionals who signpost or refer to Kooth, and from the routinely collected data from the service as a whole. Alongside this, the report provides a powerful look at how Kooth is innovating in outcome measures and responding to trends in mental health, as well as how Kooth learns from feedback to improve the service. This is important at a time where, on the trajectory out of the Covid-19 lockdowns, where 'normality' has supposedly returned, waiting lists for hildren and Adolescent Mental Health Services (CAMHS) and psychological services are at an all-time high. The integration between commissioned, digital services alongside on-the-ground services is now more important than ever, and this report highlights Kooth's mechanisms to enhance reach and engagement from young people and professionals.

There is strong evidence that service users highly value the ability to be autonomous and make choices in their mental health journey on Kooth, whilst, importantly, remaining anonymous. Removing barriers to support is critical to improving early access and prevention of mental health deterioration. Kooth has multiple mechanisms and features that can support a diverse set of users accessing the service and is seen as a digital front door for many due to no thresholds, referrals or waiting lists.

Service users reported that Kooth helped them feel heard and listened to, and there were strong indicators that service users promoted the platform to their peers. Both service users and professionals outside of Kooth highly value the out-of-hours support as well as the ability to access the platform without a referral and no waiting lists to have a chat with a professional. The report rounds off with important innovations and ways that Kooth responds to feedback, as well as how Kooth impacts the wider healthcare, social and education systems, with an exciting snapshot of Kooth's first health economic cost calculator.

#### This report dives into five main topics:

- 1. Kooth integrates with on-the-ground services to be a digital front door for young people accessing support.
- 2. Important features of Kooth that remove barriers to accessing support.
- 3. Kooth provides young people with autonomy to choose the support they want, and when they need it.
- 4. Kooth is dedicated to continually learning from feedback to improve its services.
- 5. Kooth is pioneering to be at the forefront of digital mental health support to be a critical thought partner for policy and commissioning and to support young people better.

### This report: Methodology

We used three main sources of data in this report. These included a (1) survey to service users, (2) a survey to professional stakeholders and (3) routinely collected service data.

- 1. The service user survey data was made up of 337 survey completions, out of 340 young people who voluntarily took part in the survey, which was advertised on Kooth's homepage between December 2022 and January 2023.
- 2. The professional stakeholder survey was made up of 42 survey completions by participants who voluntarily completed the survey, which was advertised over an email mailing list between December 2022 and March 2023.
- 3. The data used in this report that discusses service users engagement is from a one-year time horizon spanning April 2022 to March 2023. Additional quotes in the UX section of the report have been included from service users who have provided feedback through the platform, which is routinely collected; all other quotes are from the survey data.<sup>1</sup>

A full methodology and data section can be found at the end of the report on page 60.



# Introduction to Kooth: Kooth is a safe, anonymous, text-based digital mental health platform. We strive to be accessible to all.

Kooth is supported by decades of research conducted in collaboration with leading academic and mental health institutions in the United Kingdom. Kooth.com was launched in 2004 and is available to children and young people in the UK from the ages of 10 to 25 years old across 35 ICBs and 18 local authority/health board areas in Scotland and Wales, and recently launched in the US.

Kooth provides rapid access to self-directed therapeutic tools, peer support and professional support from any internet-connected device, without the need for a referral and at no cost to the young person, their parent/caregiver or the school. Kooth continues to promote and deliver its service model within the context of the Thrive Framework (1) which relies upon Kooth's local integration with local provider services to ensure local pathway systems are enhanced via our digital offer. Whilst Kooth is often outwardly perceived as having a focus on the Advice and Getting Help elements of the Thrive Framework, the clinically-responsive nature of our service means Kooth routinely supports young people across all of the domains (Figure 1). The flexibility and choice of the Kooth platform allows young people to autonomously access Kooth at whatever point meets their needs; then, they have the ability to move around the platform functions without having to meet threshold levels.



Kooth is continuing to work with ICS/ Health Board and Local Authority partners to enhance mental health pathways to help alleviate key NHS pressures in the UK. This includes developing new integration pathways and referral processes. We currently have a pilot programme of two new digital integrated pathways:

- 1. CAMHS wait-list support
- 2. Crisis step-down support

Figure 1: A visual representation of the THRIVE model

### Kooth provides a valuable service to young people who otherwise might have nowhere else to turn

**83%** of professionals said Kooth provides a good or great access route for young people to get mental health and wellbeing support

Almost **1** in **5** professionals could think of no alternative to Kooth in their local area when asked about alternative access points

**81%** of professionals said they would be very concerned if Kooth was no longer available in their area

**78%** of young people said they would be concerned or very concerned if Kooth was no longer available in their area

Kooth's 'end of session' feedback over the last 12 months (April 2022 to March 2023) shows that service users feel the person helping them in a live chat was a good fit in 95% of those sessions.



### Kooth removes barriers for young people accessing mental health support



### What do professionals value most about Kooth?

Free for service users to access	98%
No waiting list for professional support	79%
Easy for people to access	74%
Text-based communication with a practitioner	74%
Available for all wellbeing and mental health issues	71%
Out-of-Hours access (to a practitioner)	67%
Reduced stigma around accessing anonymous support	52%
BACP accredited practitioners	45%

### Kooth provides young people with effective, flexible support

62%

of young people on Kooth demonstrated a severe level of psychological distress



### In just the last 12 months...

**189,365** therapeutic messages were sent and **64,202** chats were delivered to young people on Kooth

**89%** of young people on Kooth used the emotions journal

Young people generated **16,038** live forum posts and **131,879** discussion board posts



66

[Kooth is]... Absolutely amazing. A very key point for me is that parents do not need to know that you use kooth. I can truly express my feelings honestly without the fear of being monitored by some parent portal. I love being able to connect with an actual professional or just a simple friendly discussion with other children. 10/10 best.

**Kooth User** 

77

9 in 10

young people rated content on Kooth as helpful

80%

of young people said Kooth helped them feel heard and listened to



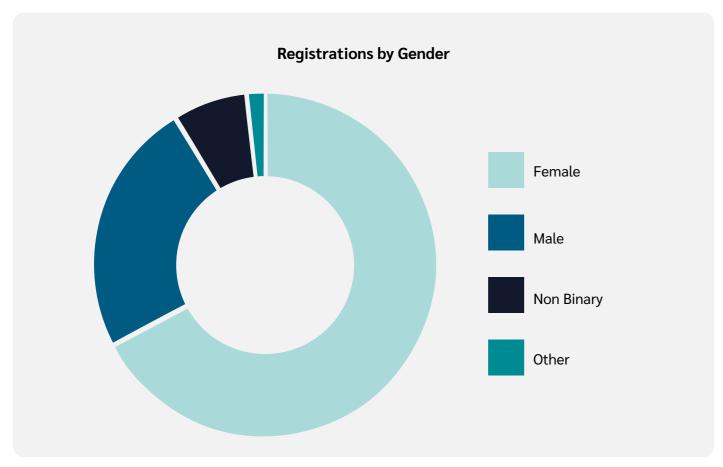
65%

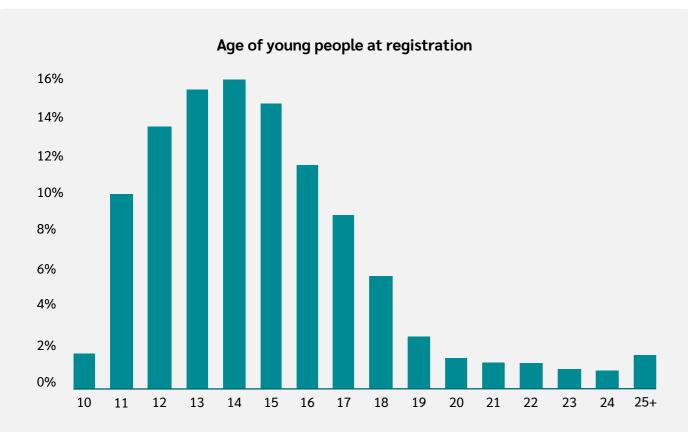
said Kooth has helped them feel less lonely and isolated

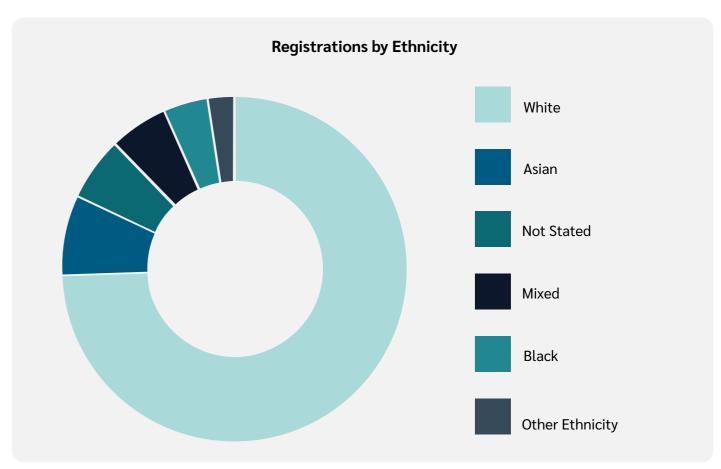
88%

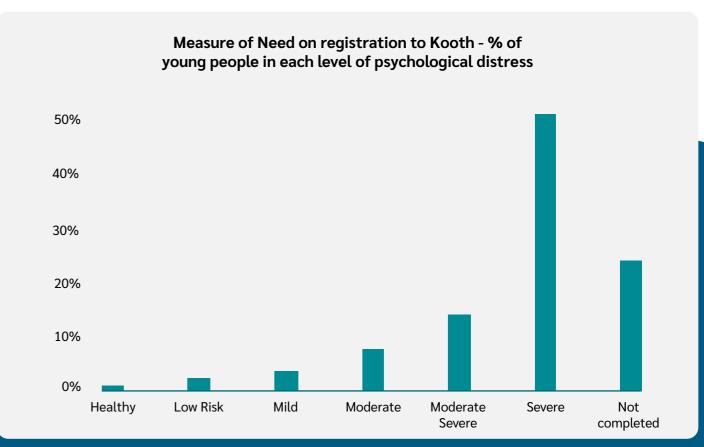
of professionals agreed or strongly agreed that they would recommend Kooth to be available in other areas 96%

of young people would recommend Kooth to a friend Kooth provides access to children and young people from a diverse range of backgrounds, many of which have severe needs.









### 1. Kooth integrates with on-the-ground services to be the digital front door for young people accessing support

A key focus for Kooth is to integrate and embed itself into local communities and on-the-ground services, as well as digital spaces, in order to be a successful pathway for young people to access mental health support without a referral. Kooth is well positioned to provide direct support to young people, but also to act as a digital front door to young people who may have not been able to seek support in the past or do not know where to go. By being integrated with other services, Kooth practitioners are able to signpost and liaise effectively to provide the most appropriate support for young people, whilst retaining the young person's choice and autonomy.

"I think it's great and it has really helped me out; it's made me have the confidence to speak to my school counsellor about a few of my problems." **Kooth User** 

"I feel like I can be responsible and ask for help myself and reach out myself." **Kooth User** 



"[Kooth is] an amazing service. Kooth has got me the best help. Kooth is the platform where I first disclosed I was being abused, and from there the counsellor got me support."

**Kooth User** 

With 20 years of experience, we have developed a robust promotion strategy. To improve Kooth's reach and accessibility, Kooth carries out ongoing engagement activities with young people, professionals, parents/carers and local organisations across the UK. Our unique approach is multifaceted, reflecting the varied mental health needs of users and audiences. Key to Kooth's promotion strategy is our engagement team: a 40-strong team of Engagement Leads, embedded in local communities. Engagement Leads work alongside our marketing team, which run nationwide campaigns and ensures resources are engaging, effective and appropriately tailored to diverse audiences.

Thousands of education settings receive regular communication including schools, school nursing, Designated Safeguarding Lead and pastoral care teams, colleges and out-of-school providers. The wide reach of school promotion ensures that CYP with a mental health need that is unknown to parents/carers or professionals can hear about and access Kooth early and anonymously. Kooth hosts regular parent and carer webinars which help parents/carers to understand Kooth and reassure them that it is safe and clinically effective. Engagement with healthcare and professional teams, such as GPs, social prescribers, charities and community groups ensures that a clear referral pathway to Kooth is established. Our Engagement Leads also deliver staff training and send regular newsletters and resources.

#### **Promotional materials**

Digital and printed assets are an important part of an Engagement Lead's 'toolbox'. Our asset library (promote.kooth.com) features a range of publicly available materials, including videos, social posts, posters, case studies and guides. New assets such as posters, leaflets and cards are added monthly and circulated to all local contacts.

Kooth has been striving to increase its social media, with a fast-growing Instagram following of 8K+ and 11K+ followers on LinkedIn. We also recently launched on TikTok, posting engaging daily content, including interviews with the Kooth team, mental health tips and anonymous poems written by young people who use our service.

Kooth's brand team runs national campaigns to help ensure Kooth is in front of mind at the point of need. Recent examples include the 'Whatever's on your mind, we're here to listen' out-of-home campaign in Manchester, where we ran creative ads across the Transport for Greater Manchester network. For Mental Health Awareness Week, Kooth ran a campaign around this year's theme of anxiety, which involved posting daily content and podcasts on the topic and running daily discussion forums on the Kooth platform. Kooth also invited young people to share their experiences of anxiety in the form of poems and letters, five of which were shared on our social media channels.

Top 5 poems from young people:



Kooth also has an extensive library of over 70 podcasts. These are accessible to service users, as well as to those who haven't registered. Issues addressed in podcasts range from anxiety and queer representation to self-esteem and gender. Some of these episodes have been designed and created by our community podcasters and focus on issues around identity, race and male mental health. Others incorporate interviews with outside organisations, such as the Proud Trust.

#### **Under-served audiences**

As a free, anonymous service, we are well placed to reach individuals who perceive mental health care as stigmatising or inaccessible. To better serve these groups, we root our work in participation. Last year, we joined forces with Blackout UK, running a series of focus groups to better understand the mental health experiences of men from ethnic minority backgrounds. We subsequently created a language charter to ensure the language in our content is inclusive and is based on the views of our workshop participants.

We've most recently initiated a project to better understand the cultural barriers that prevent many Muslims from seeking support. We are working with the national organisation Muslim Youth Helpline, as well as local Imams and clinicians to corroborate insights. The co-chair of Muslim Women's Network is working alongside Kooth to develop culturally and faith-sensitive outreach materials and training, including the creation of tailored 'Khutbah' or sermons for Imams, 'talking head' content for workshops from respected local Muslims, and integrating the benefits of mental health of meditation and prayer.

Our national partner programme goes a long way to reach children and young people who are neurodiverse, digitally marginalised, in care or living with a disability. In 2023 we will be working with national charities including Scope, National Autistic Society, Cystic Fibrosis Trust and Asthma UK, as well as voluntary groups like The Fostering Network, Gingerbread and the Citizens Advice Bureau.

Kooth has experience partnering with many grassroots football clubs that offer a key route to engage boys, young men, ethnic minorities and digitally marginalised groups. Working with holiday club providers, whether commercial organisations such as Ultimate Activity clubs, National Citizens Service or local government-run clubs, gives us the ability to inform CYP and parents about Kooth within school holidays.

#### Kooth is well integrated into local communities

Kooth is, therefore, extremely well integrated into the education and healthcare systems, providing improved access to support for young people, with Education being the highest 'heard about' option selected by young people on sign-up (Table 1). This is reflected in survey responses from healthcare, education and social sector professionals who provided feedback on Kooth:

- 64% said that Kooth was very or extremely embedded in their mental health pathways in their local areas
- 83% said Kooth provides a good or great access route for young people to get mental health and wellbeing support

Table 1: Where Young People Heard about Kooth

49%	Education
14%	Other (charity, social worker, youth services)
12%	Family/Friends
11%	Health Service/Professional
9%	Advertisement/Social Media
5%	Mental Health Service/Professional

"It's helpful, as you don't need any parent's permission, and it is free, meaning anyone can access it easily when they need it." Kooth User

#### Professionals are confident in signposting young people to Kooth

From the professionals who took part in the survey, we saw that Kooth is a 'good' or 'great' access route to mental health support for young people (Figure 2). Importantly, **88% of professionals surveyed would recommend to other professionals to signpost to Kooth.** 

 Over half a million young people and almost 300,000 professionals (from a range of professional backgrounds and provisions e.g. Education, NHS service, early help, social care, voluntary sector, etc.) attended Kooth engagement activities over the last 12 months.

Figure 2: A figure showing the percentages of professionals' views on Kooth as an access route to mental health support.

Answer	Count	Percent	20%	40%	60%
Very unsatisfactory access route	1	2.38%			
Unsatisfactory access route	2	4.76%			
Satisfactory access route	4	9.52%			
Good access route	17	40.48%			
Great access route	18	42.86%			
Total	42	100%			

"I think [Kooth] is good; I'm 12 years old and struggling with school. Yes, I'm a bit too young, or that's what people seem to [think] when I identify as or feel suicidal. Kooth helps me, and I know people who...go through the same thing, and i hope it really does help others like it does...me."

**Kooth User** 

### ...but what if Kooth was not available?

Kooth has been available for over two decades with more recent expansion into Scotland and now into the US. We are proud of this achievement as, critically, it means we can support greater numbers of young people who need help. But it is important to consider if Kooth was not available, where would young people go to or be signposted to?

As seen in Tables 2 and 3, there was a mix of alternative services that young people and professionals would go or signpost to if Kooth was unavailable. One in four young people said they were unsure of where else they would go if Kooth was not available, and 36% said they had no alternative to turn to. Other young people said they would approach someone at school or a friend or family member, however, these were not frequently reported as an alternative. Helplines were the most popular alternative source of support for young people.

Professionals' views on alternative places to signpost for support were centred around charity and third sectors as well as GPs, CAMHS and school-based services, which are already under huge pressure, with varying waiting lists and availability across the country.

Table 2: Alternative support avenues that young people would turn to if Kooth was no longer available.

Unsure of where else to go	Helplines, Text- services or Websites	Private	GP/ CAMHS/ A&E	Charity	School	Friends	Family	No alternative	Do not want to go elsewhere - privacy concerns	Would be concerned for their own safety
25%	20%	0%	4%	0%	15%	5%	4%	35%	4%	1%

Table 3: A table showing the percentages of alternative access points that professionals said they would refer to if Kooth was not available in their area.

Helplines/ Text-services / Websites	Private	GP/CAMHS	Charity	School	No alternative
19%	2%	31%	48%	24%	17%

Overall, young people were concerned where they would go if Kooth were no longer available, echoing the concerns of professionals.

### Four in five professionals would be very concerned if Kooth was no longer available in their area to signpost to.

Education, healthcare and social sector professionals who currently signpost to Kooth were very concerned, along with current users, as to what support options they would have if Kooth was no longer available. Worryingly, there were comments referring to no alternatives and a lack of clarity or understanding from young people about where else they could turn; some users also indicated no choice but to accept not being able to keep themselves safe. This is very distressing, as many young people using Kooth have severe psychological distress and complex presenting issues, and so would find it complicated or inaccessible to seek alternative support routes.

"Kooth is a free, accessible service.
Being a Kooth user for over four years means I have managed to accomplish different things and watch it change."
Kooth User

When asked to which services they would turn were Kooth no longer available in their area, young people said:

"Nowhere. [Possibly]
one teacher, but [I
would] never really tell
[them] everything, and
[I] can't do that out of
school sometimes."

"I wouldn't be able to find the courage to get support, most likely."

> "Nowhere; I would just bottle all my emotions up."

"I probably wouldn't go anywhere else for support, because I don't know of any platforms as easily accessible and private as Kooth."

"I would not be able to get support anywhere else. I rely on Kooth heavily."



When asked to which services they would signpost were Kooth not available, professionals said:

"There is very little else available. Probably GP or school nurse as well as internal school support e.g.
Learning Mentor"
- professional from. the Social / Education sectors

"GP, NHS support."
-professional
from the Social /
Education sectors

"To local mental health services within the area which predominantly have waiting lists or websites like young minds for advice and information."
- professional from the

Public Health in the

**Local Authority** 

"No idea."
- professional
from the
Third Sector /
Charity

"Would be stuck especially for those who would not meet the clinical threshold for intensive treatments, waiting lists are a real barrier also."
- professional from the Social / Education sector

"We would probably have to pay for something. It would also increase the amount of GP/ CAMHS and school counsellor referrals which we try to keep for more serious mental health needs."

- professional from the Social / Education sector

"Private services!"
- professional from the
healthcare services sector
(ie GPs, A&E, CAMHS,
practitioners)

"CAMHS"

- professional from the healthcare services sector (ie GPs, A&E, CAMHS, practitioners)

## 2. Features of Kooth that remove barriers to accessing support

It is important to consider the important aspects of why professionals from the education, social and healthcare sectors refer to Kooth, with important features of the service being: free to users to access, there being no waiting lists and the service being text-based (as seen in Table 4). This paints a rich picture as to why stakeholders value Kooth as a referral pathway.

Table 4: A table showing features that professionals said were important when considering where to refer young people for mental health support.

Free for service users to access	98%
No waiting list for professional support	79%
Easy for people to access	74%
Text-based communication with a practitioner	74%
Available for all wellbeing and mental health issues	71%
Out-of-Hours access (to a practitioner)	67%
Reduced stigma around accessing anonymous support	52%
BACP accredited practitioners	45%

Removing barriers to mental health and wellbeing care is critical to providing early, preventative care or care at the point of need. Barriers to support can be related to monetary and financial pressures, cultural norms and, more broadly to health inequalities relating to protected characteristics. Along with these barriers, in the UK there has been variability in the commissioning of services, limiting some young people from accessing services if they are not commissioned and available in their area. The disparity in provision across locations should hopefully be reduced as we move to the Integrated Care Board (ICB) system in England and as the Regional Partnerships Boards and Health and Social Care Partnerships in Wales and Scotland continue to address health inequalities. Yet, physical barriers are still very real, such as travel time to appointments or time required away from school or work to attend appointments. This is exacerbated for people living in rural or coastal towns who are required to travel to central hubs. For young people there is often a reliance on parents or caregivers to accompany or help young people access their appointments, creating an additional barrier.

### 96% of survey respondents said it was important that they could access Kooth after school or work

Other barriers can be societal, with the stigma related to mental health support still remaining high, even if awareness is increasing; this is particularly important to consider when coupled with cultural perceptions about mental health.

"I think it is very helpful for young people, because there is a stereotype linked with getting mental health support, and Kooth being anonymous really helps." **Kooth User** 

Kooth, being a digital service and offering out-of-hours chat sessions as well as 24/7 peer community and psychoeducational and behavioural health learning content, aims to remove barriers by enabling young people to access the platform from anywhere and regain autonomy and choice in how and when they access it.

- 99% of survey respondents said it was important that it's easy to access from a phone or tablet
- 61% of young people accessed Kooth out-of-hours before 9 am and after 5 pm.
- 67% of professionals surveyed said a service that was out-ofhours, like at Kooth, was a valuable feature of services they signpost to.

As seen in Figure 3, logins to Kooth are highly popular outside of school hours and late into the evening. Traditional, non-digital services are commonly restricted to working hours.

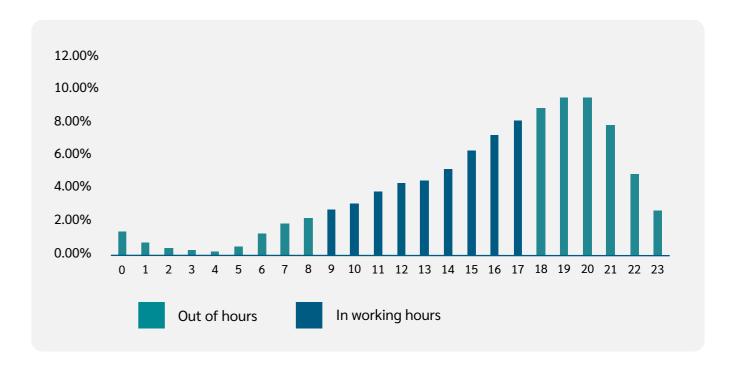


Figure 3: A bar graph showing the average percentage of logins by hour.

### Young people valued accessing Kooth after school

"I think it's great, because you can get help for any kind of mental health issue in a few clicks (however long it takes to write your first message to a counsellor). All the practitioners are really nice and caring and care so much about your wellbeing. It's also good because you can access it whenever you need it. For example, after a hard day of school, you can talk to someone on a live chat, find out ways to cope and have a much better night."

Kooth User

"I think it is great, because after school when I get home I just go on Kooth and am able to communicate with people and get help with the problems I have, so I think it is a great service."

Kooth User



### Kooth removes barriers, with no referrals needed and no waiting lists on the platform

Requiring a referral from a healthcare professional is not only a barrier to seeking support, but it also puts more demand on limited resources in the NHS and education sectors in particular.

**Strikingly, 40% of all GP appointments are said to be about mental health concerns (1)** yet GPs are not given specialist training and support to sufficiently support young people in need, coupled with the long waiting lists for treatment or MDT (multi-disciplinary team) diagnostic assessments within CAMHS; not only does this not support young people in a timely manner, but it also is not the best use of GPs' time. The complexity of referral pathways also adds to the burden GPs face when trying to support young people (2). Time from GPs and healthcare professionals can be spent on CYPs with more severe needs when referral to early intervention and prevention services is enabled.

Waiting lists are a big barrier to seeking support, with 95% of young people surveyed saying it was important or very important to them that there were no long waiting lists to chat with a counsellor. Seventy-nine percent of professionals surveyed said a service with no waiting lists, like Kooth, was a valuable feature of services they signpost to.

When we surveyed healthcare professionals, there was a clear consensus that a key benefit of Kooth was that no referral was needed, enabling quick and easy access to mental health support whilst giving the young person autonomy over their support pathway.

"[Kooth is] easy to set up and log in to which is important."

**Kooth User** 

- 97% of young people surveyed said it was important that they did not need a referral to access Kooth.
- Similarly, 95% of professionals surveyed said that it was very or extremely important that young people can access Kooth without a referral.
- 93% of professionals said they were very or extremely confident in signposting to Kooth for mild mental health needs, and 48% were very or extremely confident in signposting someone with severe needs to Kooth.

Kooth has been very conscious for many years of the considerable demand and capacity pressures facing our colleagues in specialist CAMHS teams and other providers within local CYP mental health pathways. These pressures were of course compounded as a result of the pandemic.

During the Covid-19 Pandemic and related lockdowns in the UK, waiting lists for mental health services increased, partially due to the inability to provide services under the lockdown restrictions on social distancing, but also partially due to increased mental health needs. Young people were particularly vulnerable during this time as school closures and other social youth provisions were withdrawn. Kooth saw a sharp increase in access to the platform on the onset of lockdowns with increased need seen in self-harm, suicidality and eating disorders (3). Kooth however was able to provide stability of access and care, in particular to vulnerable young people, who experienced a very separate and difficult time during the lockdowns in the UK (4).

### Kooth recognises the power of anonymity

Anonymity, privacy and confidentiality are highly important to young people when considering accessing services. 97% of young people completing the survey saying that anonymity was an important feature to them. This is particularly important to young people, but not recognised as such an important feature by healthcare professionals. This demonstrates the gap between understanding what young people want and need from mental health services, and what professionals referring and signposting to services believe young people desire. At Kooth we are trying to bring the gap in awareness and understanding by asking young people about the types of services they want support from.

- 97% of young people surveyed said it was important that they could be anonymous, on Kooth.
- Similarly 96% it was important or very important that their parents or carers did not know they were using Kooth.
- In comparison, only 52% of professionals surveyed said a service that was anonymous, like Kooth, was a valuable feature of services they signpost to.



"It's been a lifeline for me. I've always struggled with my mental health but have never been able to ask for help. For the first time in years, I've reached out and already I've been given the opportunity to live chat, I've talked to many practitioners and got so much support. If it wasn't anonymous I wouldn't have been able to reach out."

Kooth User

Anonymity enables people to access mental health support without fear of being judged for their experiences, fears and mental health needs, as well as not being a burden or worrying their parents or caregivers.

Traditionally, young people are required to discuss personal experiences, emotions or their wellbeing with their parents or carer before accessing health professionals, including mental health services. However, most young people said it was somewhat important to them that their parents or carers did not need to know they were using Kooth. Providing an access route to wellbeing and mental health services without the need for parents to know or facilitate access removes barriers to access for young people.

'[It's] good; I would recommend [Kooth] to someone else if it was appropriate. It's good it is anonymous and online, because no one is judging you and/or knows about it, so you don't have to tell your emotions to people in person, where you aren't anonymous.' **Kooth User** 

"I think Kooth is a very useful service for young people like myself who are struggling with mental health but are too scared to go to parents/school about it as they might not always react the way that we want them to."

Kooth User

"I think it's a great way to talk about emotions as it's free and anonymous. I really struggle to open up to people but Kooth is a safe space that makes me feel comfortable sharing my emotions with others as it's anonymous."

**Kooth User** 

### Young people want text-based support

Typically, digital services providing interactions with practitioners can be via video, telephone or text-based. At Kooth, we provide all of our interactions through text. This may initially be misconceived as a barrier, with less physical information and fewer cues from the young person. However, young people want to communicate through text. This is very aligned with how they communicate with their peers.

- 97% of survey respondents said it was important that chats with practitioners were text-based
- 74% of professionals said a service that provided text-based communication with practitioners, such as the service Kooth provides, is a valuable feature of services they signpost to

"People find it hard to speak on the phone with people, and the chat support is very helpful for that."

**Kooth User** 

"I think it's good for people who don't have people around them to reach out to. I find it a lot easier to talk to someone via text, because calling someone or talking face to face can be intimidating for some people." **Kooth User** 

> "It is amazing, as it's confidential and anonymous. And it's not voice to voice or face to face; it's text based." **Kooth User**

# 3. The uniqueness of Kooth provides young people with the autonomy to choose the support they want, when they need it

Kooth provides options for how young people access help, all within one positive online ecosystem of support. Service users can choose to complete onboarding assessments or skip these; they can choose to read and engage with peer content or request a chat with a professional. As seen in Figure 4, there are pathways of support, from therapeutic content and peer support, to single-session chats, to more structured and ongoing work with professionals.

### Therapuetic Content and Peer Support

CYP who read content online, create online content from personal experience and participate in peer support discussion forums with others.

### Reactive/Responsive Therapeutic Support

CYP who have between one and nine sessions of chat with a Kooth worker over a non-specific time period, without being offered or accepting a structured series of chat sessions

#### **Structured Therapy**

CYP are offered a series of chat sessions (up to 10) by appointment with a named practitioner

### **Ongoing Therapuetic Support**

CYP who attend more than 10 sessions of chat. This might take place over an extended period, possibly years

Figure 4: Engagement pathways in Kooth.

Young people engaged with a range of tools on Kooth over the last year, with journalling and goal setting being particularly popular amongst young people, providing self-directed therapeutic tools to engage with. As seen in Figure 5, young people can provide emoji journal responses, with a range of positive and negative feelings to pick from.

Neutral		Positive			Negative	
I'm not sure	Slightly smiling	Нарру	Calm	Upset	Angry	Worried
22%	24%	22%	17%	6%	4%	4%

Figure 5: Visual of the emotions mood journal in Kooth and the percentage of each selected.

"I feel like Kooth is a great service to young people, [with] the way there is a range of things to do, and how to do them. For example, say someone didn't want to speak to a professional. there's always the option for the forum comments."

**Kooth User** 

#### Highlights of what young people engaged with on Kooth:

- '89% of young people used the emotions journal equating to more than 105,000 young people.7
- 79% of survey respondents said it was important that they can create and set goals, with 20% of engaged users setting goals - that is a massive 24,849 young people setting goals on Kooth.
- 13% of users engaged in chats with practitioners that translates to more than 15,500 sessions with young people.
- 6% of engaged users over 6,600 young people created or commented on articles in the community space.

Giving young people autonomy and choice is an important way to encourage and enable engagement with mental health services.

said it was important or very important that they had a choice in what they did on Kooth.

"It's amazing, most mental health services you can only speak to the professionals but on here you can speak to both professionals and young people." **Kooth User** 

### The Power of Peer Support

Kooth's unique online peer community provides therapeutic value to young people, with a recent evaluation conducted by LSE, which found that using the Kooth online community led to improvements for young people over a month of using Kooth (6).

To explore the benefits of Kooth's online peer community, Kooth has developed the Peer Online Community Experience Measure (POCEM) (7). The POCEM enables users to provide feedback on whether the content articles they are reading are helpful to them, it also helps our professional content creators determine which content in the community space is beneficial to users.

### When young people were asked about the peer community features:

- 93% of young people said it was important to them to be able to find articles that are informative to them.
- 90% of young people said it was important to them to be able to join a forum or discussion board on a topic that interests them.
- 85% said it was important to be able to write articles about their experiences or emotions.
- 95% said it was important to be able to ask the peer community for support.

36 <sup>7</sup>119,402 active users (excluding viewers) 37 "Whenever you post something worrying, there's always someone reaching out and offering support." **Kooth User** 

"It's good to write down how you feel each day and get support if you're not doing too well."

**Kooth User** 

"I really like it, and it is helping me, because if I don't feel the best, then I can do an activity, or write in the emotion[s] journal, or write an article or discussion [post], or read through other people's [articles and posts]."

**Kooth User** 



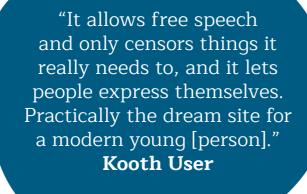
### Kooth ensures a safe, positive, virtual ecosystem

All content submitted on the Kooth platform is moderated. This ensures our community of service users are safe. Moderation can trigger safeguarding action too, providing a vital risk management mechanism for users not choosing live chats. The moderation processes ensure young people are experiencing a safe and trusted virtual digital ecosystem, where peers can engage, connect with one another and express themselves.

Moderation also prevents information sharing, such as names or locations, and it prevents harmful or disrespectful posts from being shared. This fosters a positive virtual ecosystem where young people can safely express their emotions and support other users, with theorised benefits of digital altruism, improved mental health literacy and reduced isolation and stigma. A case study of Kooth's moderation processes highlighted the importance of skilled moderators who have intellectually and socially grounded skillsets, with specialist knowledge (5).

"[Kooth] completes its goal of being a safe place for young people to express themselves and not feel confined by societies' images of what is normal, as here we express what actually is normal."

**Kooth User** 



"[Kooth] offers a way to connect with others in an age-appropriate environment."

**Kooth User** 

"It is amazing, as it's confidential and anonymous. And it's not voice to voice or face to face; it's text based."

Kooth User

### Kooth has supported young people in a range of ways, meeting their wants and needs

The Kooth Theory of Change (6,7) discusses the matrix of support needs (see Figure 6) which shows the interplay between information, emotional support and interpersonal and intrapersonal needs. We see that service users' wants and needs map onto these quadrants. The types of features on the Kooth platform aim to align to provide these wants and needs to service users.

	Emotional Support	Informational Support
Intrapersonal	e.g. "I understand myself more"	e.g. "I can identify with something important to me"
Interpersonal	e.g. "It helps me relate to others"	e.g. "I have some skills I want to try with others"

Figure 6: Matrix of Support Needs from Kooth's Theory of Change (ToC)

When we asked young people who took part in the survey, we saw that Kooth has helped them to feel heard and listened to, feel less lonely and isolated and find useful resources to help them understand their emotions and behaviours as well as find out about support options.

"[Kooth] Helps me realise that I'm not alone in my issues without making me feel insignificant"

**Kooth User** 

"I think that it's an amazing service that has given me the opportunity to feel heard in times of need."

Kooth User

"I think it's very helpful for people who need support but can't go to those around them. I have recommended it to friends and they have continued to use it."

**Kooth User** 

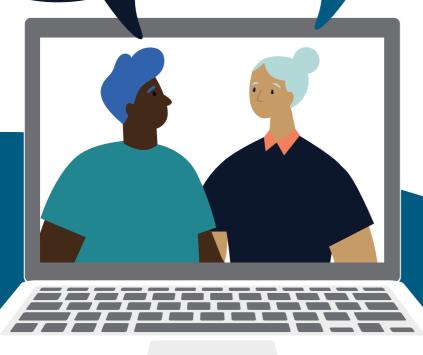
"It is good that it makes you feel safe."

**Kooth User** 

"It is a useful and productive service that helps young people feel listened to and appreciated."

Kooth User

"Kooth has helped me just talk about things I never felt I could with anyone else." **Kooth User** 



#### Other aspects that Kooth helped young people with were;

to feel heard and listened to	80%
to feel less lonely and isolated	65%
to find useful resources to help me understand my emotions and behaviours more	62%
to find out what support is available to me	60%
to feel more connected with others	48%
to manage negative behaviours	45%
to achieve my goals and aims	30%
to be more confident to seek support from parents, friends or school	30%
Other	10%
N=337	

Table 5: Young people's responses to the question 'What has Kooth helped you with?'

### Young people are highly satisfied with Kooth

How satisfied young people are with the Kooth platform and service is vitally important to us, to help us ensure that we are providing what young people want and from Kooth. Satisfaction is one way to examine how appropriate the service is.

From examining different data sources, from the service user data to the survey responses, young people are highly satisfied with the Kooth platform and service. We see high levels of satisfaction with both the platform and professional support from chats (Figure 7). Lots of young people say they would recommend Kooth to a friend, that they got what they wanted from the platform and that those supporting them in chats were a good fit.

- 86% of users<sup>13</sup> said they would recommend Kooth to a friend.
- 90% of users said they got what they were looking for from Kooth.
- 91% of survey respondents said they were satisfied with the features of Kooth.
- 88% of survey respondents rated their experience on Kooth as four or five out of five, where five was a great experience.
- 95% of service users who completed the end of session questionnaire said that the practitioner helping them in their live chat was a good fit.

Kooth's 'end of session' feedback over the last 12 months (April 2022 to March 2023) shows that service users feel the person helping them in a live chat was a good fit in 95% of those sessions.

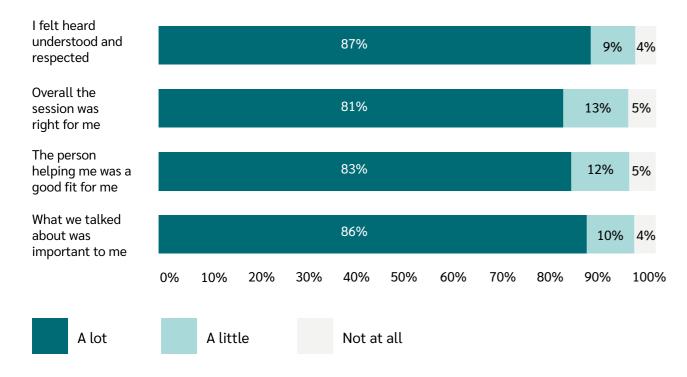


Figure 7: Service User End of Session Feedback, completed after chat session with a professional.

"I genuinely think Kooth is one of the most important and beneficial platforms I've come across. It was the first place I came for help about four to five years ago and was so helpful, as it meant I had someone to tell about my anorexia before I got put in treatment. It's a very isolating disease, and there wasn't a single person who knew about it at first, but Kooth was there, be it through the journal or messages. The anonymity made me feel safe and able to be more open about it as well. I can't thank you guys enough or emphasise just how much of an impact you have had on (I'm sure) so many young people. The platform itself is very easy to use, and everyone I've spoken to has been so kind and understanding as well."

### **Kooth User**



# 4. Kooth is dedicated to continually learning from feedback to improve its services

Kooth is dedicated to continually improving and advancing the platform and service. We do this through learning from feedback from users and commissioners, as well as our insights, clinical and research projects. We proactively use this information to improve our platform experience and to inform our commissioners of the key issues our service users are highlighting.

### We have highlighted here some of the ways that Kooth learns from feedback...



### ...Through championing lived experience and user participation

Kooth has always believed in learning from and working alongside people with lived experience. We strive to embed this principle into all of our teams so that young people are involved in decision-making and in the development of our services. Kooth has developed, with the organisation 'Participation People', a toolkit to help guide and train staff in conducting meaningful participation.

Some of the areas that young people have been involved with in Kooth are discussed below; key areas of involvement span research, usability testing and design, product development as well as data science applications and clinical validations with users.

Kooth has been expanding the network to improve the reach of participation and lived experience work, broadening the representation of lived experience members. Kooth has collaborated with the Participation People, The Independent Mental Health Network (IMHN), BlackOutUK, Dscount and the Anna Freud Centre with CORC, to name a few. By collaborating with participation experts and networks we ensure that we can provide a fairer and more diverse representation of young people across the UK.

In 2022 Kooth was shortlisted for the Collective Power Awards, which was run by the Culture, Health and Wellbeing Alliance, celebrating the lived experience participation work. The project we were shortlisted for was the co-creation of a language charter to have more effective and relevant engagement with men from ethnic minority backgrounds. The language charter is now available for all Kooth staff to access and utilise.

Kooth was also recently featured in an OFCOM report highlighting our work with Blackout and Cultures CIC in 2022. The work focused on learning what underserved groups with lived experience want and need from digital mental health services.

### ...Through putting users at the heart of product changes and improvements

Involving young people in the development of Kooth is crucial for creating a user-centred experience that effectively supports their mental wellbeing. Through feedback and user research, we identified usability issues and made significant changes to improve the product. In the following examples, feedback was gathered on the platform. This identified where users wanted to have an improved experience. Kooth's design and user research teams then explored improvements and tested improved designs with young people.

Some user feedback was about the navigation of the platform. Some struggled to find their way back to the home page after navigating away from it. As a result we added a clear "home" text label under the Kooth logo to address this. These changes have made navigating the website easier and more intuitive. Small changes like these can be overlooked or seen as obvious, but these make a big improvement to the accessibility of the platform.

Another area of improvement was the community forum. "I've always wanted this and it will make it so much easier to find specific posts that may be helpful. I also think we should be able to see all the posts and articles we have made, or be able to monitor them." Comment from a service user. Feedback from users indicated that finding forum posts related to their interests was challenging. Based on this feedback, we introduced search functionality to the forum. This addition has been well-received by service users, who have expressed appreciation for being able to easily find specific posts that are helpful to them. They have also provided suggestions for further enhancements, such as the ability to monitor and access all their own posts and articles. From this feedback we included a "my recent posts" section on their platform home feed, to enable easier access to a user's posts and recent comments.

By actively involving young people and listening to their feedback, we have been able to address usability issues and make meaningful improvements to Kooth.

Our users requested avatars with headscarves so that they could pick one that represented them. The product team designed and released a new range of avatars featuring hijabs and shaylas.



**Kooth User** 

### ...Through enabling data science product improvements

Kooth's data science function engages extensively with stakeholders to explore how to improve the platform from a safety and usability perspective. One recent improvement has been to examine content personalisation solutions for Kooth, which has involved extensive consultations with service users and internal service providers. Feedback and insights were gathered on five potential solutions, and each was assessed based on risks, requirements, and suggestions.

Content search abilities were something that also was highlighted in the service user survey as a point of improvement. "[Kooth is] good but would be better if you can search for a specific topic on the articles... as there are so many I find it hard to go through them all to find one that interests and helps me" Kooth User and "[Kooth] could have a search thing on a forum so we can find the discussions we really care about" Kooth User.

Following exploration and consultation, a consensus was reached that search should be integrated into Kooth's platform. The decision was made based on the benefits of search functionality for service users and the feasibility of integration. The forum search is now available on our platform, with plans for further expansion in the future, which will improve the experience for users on the platform.

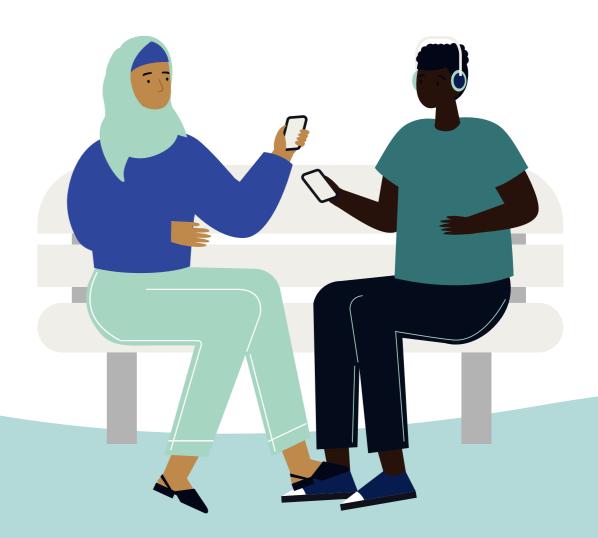
Kooth's Youth Leadership Team (YLT), were highly involved in this project and whose input was particularly valuable in ensuring alignment with the needs and preferences of our service users. Going forward, we remain committed to stakeholder engagement and to making decisions based on a range of perspectives and experiences.

### ...Through focusing our research on young people's wants

Kooth's marketing team conducts regular research with young people to improve the offerings of Kooth, but also learn more about what they want and need to improve our reach and engagement.

As an example of this, Kooth's marketing and content teams recently ran a survey on inviting our users to help shape how we deliver content and community discussions in a way that really works for them. For example, when asked about the type of written article they'd find most helpful, our users said they'd find "practical ways you can cope" most helpful. Coming in second place, out of a possible five options, was "real life personal experiences of others".

With this insight, our marketing and content teams ensure we're providing valuable, therapeutic content informed by the views of our existing user community. This is also vital in informing the marketing content we create to reach young people who might not be aware of Kooth.



## 5. Kooth is at the forefront of Digital Mental Health Support

Kooth strives to set and respond to trends in mental health, both in relation to service user wants and to changes in policy and commissioning. Some of the more recent and ongoing work relates to how Kooth is championing the single-session model, providing timely, responsive and solution focused support for young people.

#### Single sessions and SWAN-OM development

Single sessions are highly popular on Kooth and are an important way to provide solution focused, brief and immediate support to young people. As a result of its popularity, and the lack of easily applicable outcome measures the impact of single sessions, Kooth has been innovating in outcome measures specifically for this purpose.

Kooth has developed the Session Wants and Needs Outcome Measures (SWAN-OM) based on the theory of change as well as involvement with clinicians and young people (11). The SWAN-OM has had good uptake from our practitioners and users, providing a framework to focus sessions as well as provide outcomes.

In 2022, Kooth worked with Child Outcomes Research Consortium (CORC) to validate this new measure and has published a peer-reviewed journal on the evidence showing good concurrent validity of the SWAN-OM (12)). Development and evaluation of the SWAN-OM are ongoing, with an existing trial with face-to-face providers to examine its acceptability and validity with face-to-face providers.

Link to our report on Single-sessions



SWAN-OM validation paper





### Kooth partnered with leading health economists, YHEC, to create a bespoke cost calculator to estimate the cost savings to the UK government

Kooth has also started examining the health economic impact of the service and platform on the wider UK Government systems. Kooth partnered with the York Health Economic Consortium (YHEC) to develop a cost calculator based on an early cost-consequences model (13)N). The cost calculator can be used to calculate real-time cost-aversion for specific contracts and geographic areas.

For the base case example (Figure 8), the findings follow a cohort of 2,160 real young people through the contract over a one-year time period. In this time period, 1,987 young people had an emerging mental health need (EMHN - defined as having been identified to have moderate or worst psychological distress). Of these young people, it was assumed that 75% would have had a GP appointment if Kooth was not available; of these, 20% would have needed follow-up appointments and would have been prescribed medication, and 25% of these would have needed additional GP support after being rejected from CAMHS.

As well as this, the cost-savings are due to averting (when following the base case young people (2,160 users) over a 1-year time horizon):

- 19 individuals from hospitalisation due to suicidal ideation or self-harm.
- 3 individuals from being arrested for committing a crime.
- 40 individuals not practising smoking.
- 28 individuals not practising in binge drinking.
- In addition 35 individuals were estimated to attain at KS3 level and 60 individuals at KS4 level following use of the Kooth platform (no cost savings were attributed to this in this model).

"I think Kooth is amazing. It's helped me a lot when it comes to school and my confidence. It's just so wonderful to be a part of." Kooth User

### Cost-avoidance model assumptions:

Clinical experts determine two scenarios and funneling (GP and medication) routes of impact that Kooth will avoid if present for those who are known to have EMHN and engage with the platform.

The **base case results** followed a cohort of 2,160 young people from a typical Kooth contract over a 1 year time horizon with a contract cost of £140,000.

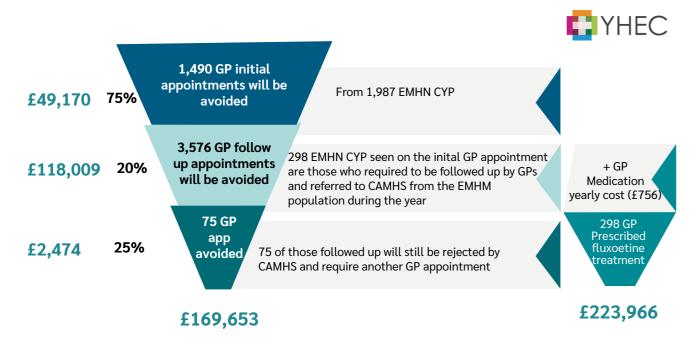


Figure 8: A flow diagram showing the major cost savings due to aversion of GP and medication use in the Base Case example.

• In the 'default base case' example, for every £1 spent on Kooth, there was a £3.16 saving to the UK government and NHS.



Check out the pre-print of the peer-review journal article which discussed the assumptions and conservative nature of this model as well as the potential for future improvements. The wider impact of education for example was theorised but not costed for in this model.

"I think this service is great! It's anonymous, free and effective! I can talk to people of my own age in similar situations, I can receive more professional help without having to admit to family/friends or a doctor in person to seek help here either. As a 15 year old who struggles a lot, I find Kooth a daily support, and the fact my parents don't have to know is important to me:) I can access help and answers to issues I may have, and distractions such as reading other members' creative writing are great fun and super useful on top of everything! I am so thankful as I'm able to have a key worker, too, as this makes me more comfortable and open, meaning more support is available in the long run. Such amazing workers and team, 10/10. Definitely, the best mental health service I've tried online, especially since it's free.:) "

### **Kooth User**



"Kooth has helped me stop self-harming."

**Kooth User** 

### Summary

Insights from this report demonstrate that, over the last 20 years, Kooth has integrated with on-the-ground communities and local, as well as national services/ provision to provide a barrier-free access route to mental health support. The link between Kooth and in-person services improves access and reach, with a current focus on under-served populations. By working with local providers and community groups, Kooth is providing access and a wide reach to diverse populations. Integrating digital providers into physical spaces is critical, with a clear benefit of working with schools and the education sector to provide a whole-school approach to mental health support, as well as with GPs and healthcare providers and local authorities. This is important at a time where waiting lists for CAMHS and psychological services are at an all-time high. The integration between commissioned, digital services alongside on-the-ground services is now more important than ever.

When young people and professionals were asked about where they would go or signpost to if Kooth was no longer available in their area, the results were conclusive: for many, there were no clear alternatives to Kooth. When there were alternative services, they were already under-resourced or over-used. Additional pressure would be placed on these services if Kooth was no longer in place to support young people. Both professionals and young people showed concern at the idea of Kooth not being available in their area.

In a digital age, now more than ever, young people are engaged in and sharing their own mental health journeys. Kooth recognises the power of young people's voices and is committed to providing a service that meets their wants and needs. Having a long and rich history, it is not surprising that Kooth fulfils many of the desired service features that young people said were important to them. Young people said they wanted anonymous, free, flexible and easy-to-access support, with out-of-hours and referral-free access routes. Professionals who signpost to Kooth also valued these features, in particular the lack of referrals needed, the text-based nature of Kooth and the choice it provides, with anonymity as standard. This report demonstrates that, overall, young people using Kooth are highly satisfied with the platform. They felt heard and listened to after using Kooth, and there were strong indicators that service users promoted the platform to their peers. As Kooth tries to increase its reach to underserved communities, bringing in non-user lived experience and participatory groups offers an excellent avenue to gain more

diverse feedback. Kooth has demonstrated success in this, having been shortlisted for participation awards in 2022, and Kooth will continue to champion this approach through working with organisations such as Muslim Youth Helpline, charities such as Scope and National Autistic Society, as well as voluntary groups like The Fostering Network and the Citizens Advice Bureau.

Kooth strives to be continually improving, innovating and not only responding but informing on trends in the digital mental health field. This report showcases some of the innovations in the measurement of single-session interventions, with the SWAN-OM development, as well as a bespoke cost calculator for Kooth, created by YHEC. These tools are just part of the work Kooth's research team are doing alongside leading academics. We continue to respond to trends in the mental health field, in terms of what young people want, but also in relation to supporting commissioners in what they need to assess the utility of digital mental health platforms.

"I wouldn't be here without it, so thank you so much." **Kooth User** 



"[Kooth] is a great source for young people to open up about their feelings without fear. It has helped me and many others a lot."

**Kooth User** 

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### **Appendix**

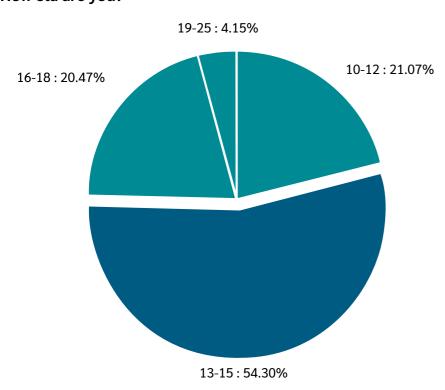
#### **Survey Uservoice Survey Methods**

The purpose of the 'young people's views survey' was to gain a better and up-to-date understanding of Kooth users. We ran the survey over the new year period to enable Both teams to embed the responses and feedback into their new project for 2023.

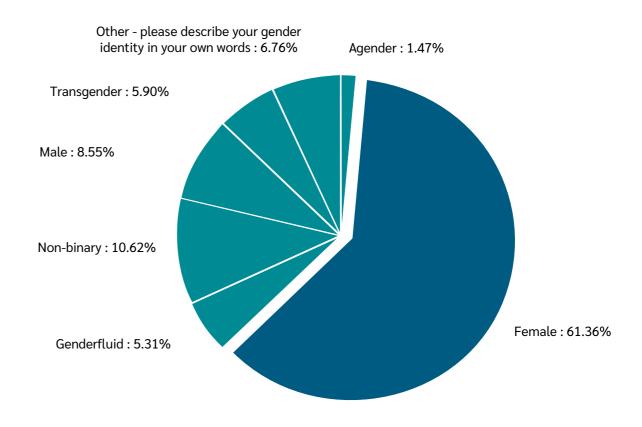
A total of 340 young people took part in the survey, and of these 337 completed it. The survey was live from the 19th of December 2022 until the 26th of January 2023. The survey was live for only 6 weeks, this was to strike a balance between collecting more data and having enough data to be representative of a range of Kooth users. We try to keep surveys off the platform as much as possible to try to not detract from the therapeutic content.

Service users completed the survey voluntarily after seeing an article asking for their feedback. The survey took on average 5 minutes to complete. The survey was created on QuestionPro and so all users remained anonymous, with no IP or email addresses being stored.

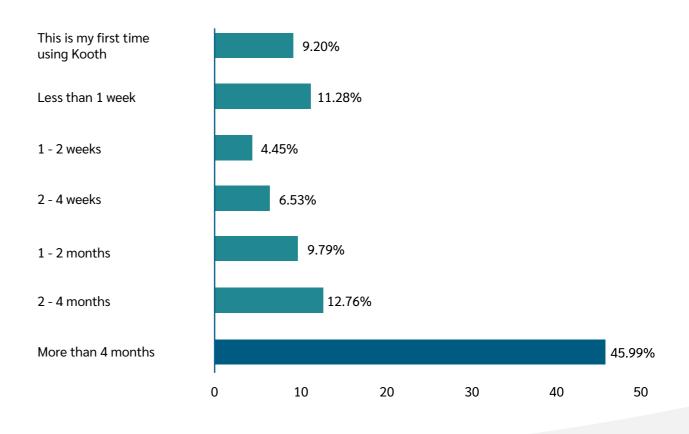
#### How old are you?



### What gender do you identify with the most?



#### How long have you been using Kooth for?



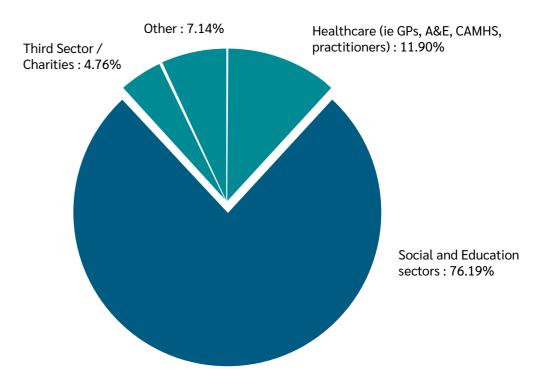
### What parts of Kooth have they used?

Live chat support with a counsellor	61%
Messaging Support with a counsellor	70%
Reading Articles	80%
Writing Articles/ Commenting on Articles	43%
Peer to peer support (forums) / Discussion Boards	54%
Mini-activities	40%
Goal setting	48%
Emotions Journal	74%

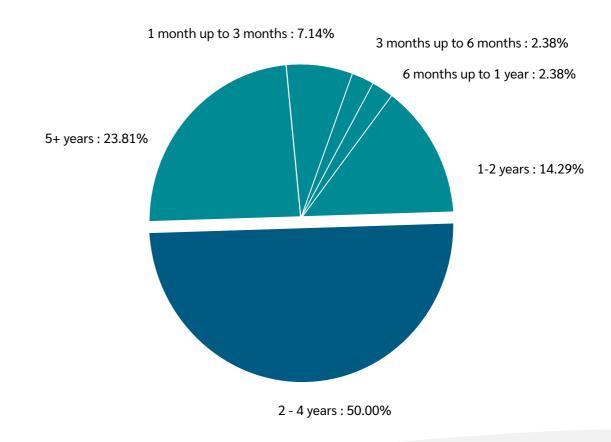
#### **Professionals Survey Methods**

The purpose of the 'professional's views survey' was to gain a better and up-to-date understanding of Kooth and the integration of Kooth in the wider healthcare, social care and education systems. We ran the survey over the new year period to enable Both teams to embed the responses and feedback into their new project for 2023. 42 professionals took part in the survey, all of which completed it. The survey was live from the 19th of December 2022 until the 28th of March 2023. The survey took on average 7 minutes to complete.

#### What sector do you work in?



#### How long have you been signposting to Kooth?



### **Acknowledgements / Contributors**

Thank you to all the service users and healthcare, education and social sector professionals who took time out of their day to complete the surveys that helped inform this report. We also acknowledge the contributors from across Kooth;

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