Kooth Digital Health: The Healthwatch Report

Waiting Times, Thresholds to Access and the Democratisation of Mental Health Care.

Reflections on the State of Mental Health Services in the UK.

A Kooth Report

Introduction & Background

It is clear mental health services are struggling. To say so has become a cornerstone of healthcare dialogue, almost to the point of desensitisation.

The Covid-19 pandemic, staffing shortages, the increasing level of acuity in presenting issues and inpatient bed shortages have only exaggerated pressures on overstretched clinical pathways.

As the largest provider of digital mental health services in the UK, Kooth Digital Health is in a privileged position to be able to see emerging trends in mental health needs from the thousands of service users who log-on to our platforms everyday. We share this information with our colleagues and partners in the NHS and across the Health and Social Care space, both locally and nationally (all UK nations), through our regular data-rich reporting and publications. From our work with Healthwatch branches at a local level and from Healthwatch publications we were aware that Healtwatch holds a key role in this picture. Through seeking and hearing patient voices and stories about what it is like to ask for help from health services, healthwatch was performing vital work to ensure the continuity and amplification of the patient voice. We therefore commenced a project at the end of 2021 to gather some of this information from Healthwatch branches across the country and to piece this together with our learning.

Responses to this Healthwatch mental health survey and the subsequent Healthwatch web event hosted by Kooth in March 2022 revealed that the challenges with access to mental health support are something that local groups and, by proxy, the service users around them are all too aware of.

As this brief report will outline, the discussion revealed that the main concern of the patient representative bodies was **waiting times** for support, **thresholds to access** for certain services, and the **uncertainty** brought on by the introduction of **Integrated Care Systems.**

Main Findings

First, we examined ease of access to services as and when needed in general. Every respondent to our Healthwatch mental health survey (N=41) thought access to mental health services for CYP and adults alike was a key issue.

Access to mental health services remains poor and disproportionately affects those from disadvantaged backgrounds, the black and non-white community, and amongst rural populations. Assessing why this is the case quickly became a cornerstone of the discussions during the web event as well as this report will go on to highlight.

When asked what they thought the major access challenges were for CYP mental health support in their area, over 70% (70.6%) of respondents believed waiting times were a critical issue to preventing access.

While discussing the beleaguered services in their area during our workshop discussions with local Healthwatch groups, a similarly bleak picture emerged. In many cases, the national level statistics presented on waiting times appeared to mask the individual cases where, according to one Healthwatch representative, certain service users were waiting for up to two years post assessment for mental health support. While these unique cases appeared to be presenting with acutely complex intersecting needs, such time frames remain alarming. It was also clear that across CYP and adult services it was standard practice to offer an initial appointment and then place service users back on a waiting list for further support. It is these unmeasured wait times - known formally as hidden waiting lists - that are perhaps the reason for such disparate time periods in the national statistics to those presented by Healthwatch representatives.

Some positive moves were drawn out in these conversations too, however. There was substantial praise for community services provided by VCSOs as they continue supporting individuals while they wait for statutory services. Unfortunately however, it was identified that when service users do receive an assessment with CAMHS or a Community Mental Health Service, they are often then instructed to access the community service from which they came.

While the NHS' Long Term Plan outlines a plan to reduce waiting times for CAMHS to a national standard of 4 weeks, with the current volume of individuals attempting to access services, waiting times have sky-rocketed to well above this guidance.

Only 25% of all young people who had been referred saw a practitioner within this timeframe (NHS Digital MHSDS, "Additional statistics to support the measurement of waiting times into children and young people's mental health services 2020-21", requested by the OCC).

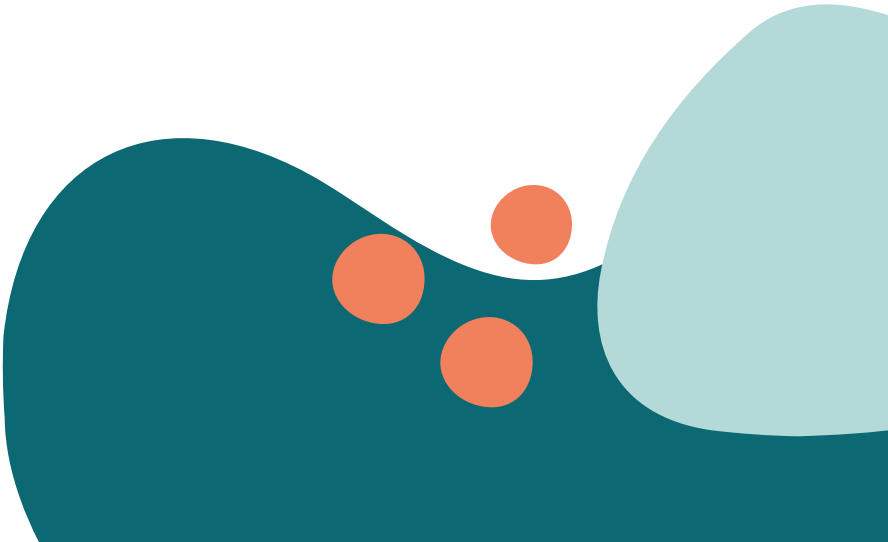
Adult services, despite a dearth of media attention compared to CYP services, are afflicted with even longer waiting times. Almost three quarters of respondents (73%) agreed that this was a key barrier to access for the 18+ population in their region. One Royal College of Psychiatrists report reveals just how accurate this assessment is:

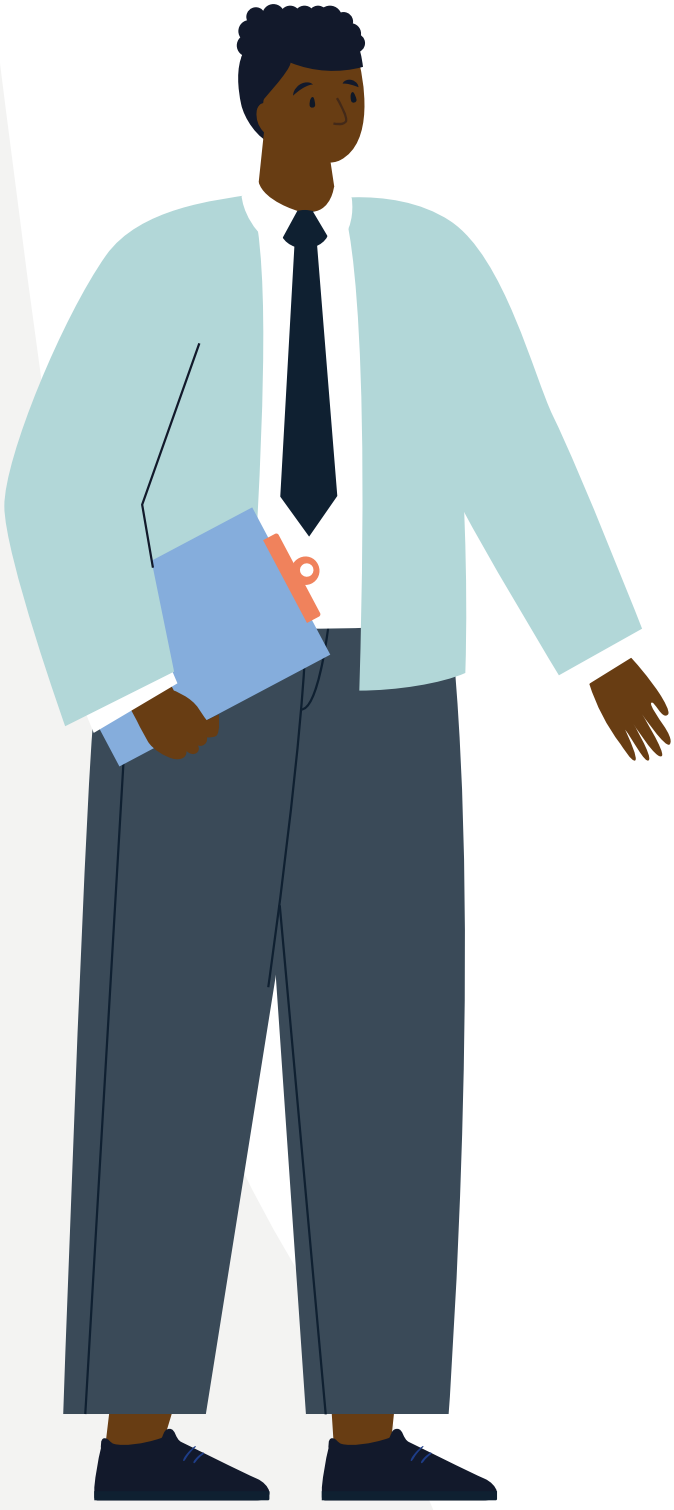
"Of those on a hidden waiting list*, nearly two thirds (64%) wait more than four weeks between their initial assessment and second appointment. One in four (23%) wait more than three months and one-in-nine (11%) wait longer than six months." (Royal College of Psychiatrists, Oct 2020)

*Hidden waiting lists are the time between a patient's referral and their second appointment.

The need for a solution to these issues is paramount to ensuring the continued efficacy of mental health services. Kooths digital platform offers, if not a panacea, a definitive piece of this collaborative puzzle. By holding users waiting for referrals and mitigating the potential for worsening acuity in presenting issues, service users are presented with an option for support in the interim, ultimately relieving waiting list pressures on the crisis services patients turn to in need. Our data shows positive outcomes for those in the early intervention and prevention bracket of support too, removing strain on in person services and allowing a greater focus on digitally impoverished groups.

Furthermore, 63.2% thought thresholds and criteria for access were a major access challenge for CYP services - a number which rises to 70.6% for adult services. In more detailed feedback given and during our discussions it was highlighted that this can be particularly challenging for individuals with complex needs, such as CYP with special educational needs or adults who are using substances or alcohol. Individuals are being passed from one service to another or worse, simply having their referral rejected, with little communication between services.





Additional Findings

Aside from waiting times and thresholds and criteria for access, a further selection of qualitative responses were particularly interesting:

Cultural barriers in talking therapies

Reflections were made on the increasingly insurmountable cultural barriers to access in talking therapies.

Our anonymous platforms' strength emerges from its ability to break down such barriers as individuals can engage with our counsellors harbouring no preconceived notions of cultural disparities or potential misunderstanding. Furthermore, Kooths organisational strength is in its diversity and collaboration - all practitioners communicate regularly and in real time with our network of Emotional Wellbeing Practitioners, Counsellors and Clinical Psychologists from a wealth of backgrounds to ensure a sensitive and coordinated approach to cultural barriers.

Logistical access

Rurality, distance, and transportation are all barriers to access for many.
This was also something that was picked up in the workshop discussions we had during our web event. Specifically, many believed that the formation of ICS's would inhibit those furthest from care hubs from receiving specialist or targeted support. While by no means a holistic solution, digital services can overcome these barriers in provision while the gap can be bridged - and indeed can continue to support once it has been.

Opening times

42% of respondents thought opening times were a barrier to access for both CYP and adults.

This is confirmed by data from our online platform, we see that the majority of our users - 65% of all contacts - are accessing online support out-of-office hours. Indeed, in the workshop discussions at our web event, representatives were keen to highlight out of office hours support as critical with one representative suggesting that 'there is certainly a need to look at services available outside of Mon-Fri, 9-5pm and not just have crisis services available outside of these hours. It is important to provide more choices for young people and adults'. Digital services like Kooth help manage and prevent worsening acuity in these moments where conventional services are unavailable.

When respondents were asked about specific mental health wants and needs for CYP in their respective region, responses focused heavily on the need for early intervention and prevention, the impact of waiting for assessments and the lack of support in the interim (specifically around ADHD and ASD for CYP but also other mental health issues), and, once again, waiting times.

Prevention was also mentioned - too often are individuals turning up to services already in crisis. In the same RCPsych paper previously cited, it is stated that "two-fifths of patients waiting for mental health treatment are forced to resort to emergency or crisis services". (Royal College of Psychiatrists, Oct 2020).

For children and young people, transitioning from CYP services to adult services too is an issue that was mentioned a handful of times. The sudden drop off in support at 18 results in a feeling of starting again - once again, a chasm that could be bridged with the use of digital services. Kooth's CYP platform, for example, has the capacity to engage with users up to the age of 25 to help smooth this transition.

Within our workshop discussions, service user engagement was often brought up as a critical facet of service provision. There was a desire amongst representatives to work closely with Kooth and our KELs (Kooth Engagement Leads) and QELs (Qwell Engagement Leads) - our local, place-based representatives who work with community organisations to promote our service - in regions where our service is present to strengthen the relationship and mutual advocacy between Healthwatch and Kooth.

All of these issues allude to one main concern: a lack of integration between services. One poignant quote from a respondent encapsulated the state of services well: **"There should be no wrong door"** for patients seeking support. All services should be interoperable and agile in their ability to refer users to other, more relevant services, without them having to leave the system and try, to maintain the metaphor, another door.

Working with the emerging ICS structure

As the structure of the NHS continues to evolve, and ICS's form from their constituent regions, we ended the survey by asking what Healthwatch organisations felt their constituent patients knew of the impending changes and how many questions they were receiving about them. Overwhelmingly, the answer for the general public was no. Awareness of these changes is therefore very low amongst the general population.

When asked how Healthwatch, the voluntary and community sector and Independent Health and Social Care providers were represented or involved in these structures, the answers were varied. Frequently used language ranged from "poorly", "unsure" and "unclear" to "very strongly" and "involved at all levels". When discussed in the workshop session, representatives revealed that they are often involved in email chains as a courtesy and for visibility but their involvement and influence at board level is sometimes questionable. For the benefit of the patient voice at ICB level, more interaction would be crucial. Conversely however, many believed their leadership - specifically CEO's - were to some extent involved which ultimately translates to patient representation at board level. As the ICS's are all at differing stages of development, this could account for this vast range in responses - but is interesting to note nonetheless.

Conclusions

This short report has reflected on the state of mental health services in the UK from the perspective of Healthwatch and the patient and revealed staggering shortcomings in waiting times and thresholds to access.
In doing so however, we also unveiled incredibly positive reflections on community support and improvement nationwide as organisations come together to tackle the problem head on. Ultimately there is some way to go - but the solutions are emerging and Healthwatch and Kooth alike remain the frontline of democratising access to mental health services.

References:

"Two-fifths of patients waiting for mental health treatment forced to resort to emergency or crisis services", Royal College of Psychiatrists, Oct 2020, accessed on 02/04/22 (https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2020/10/06/two-fifths-of-patients-waiting-for-mental-health-treatment-forced-to-resort-to-emergency-or-crisis-services)

NHS Digital MHSDS, "Additional statistics to support the measurement of waiting times into children and young people's mental health services 2020-21", accessed on 05/04/22 (https://digital.nhs.uk/supplementary-information/2021/waiting-times-for-children-and-young-peoples-mental-health-services-2020-2021)

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