

# Digital Mental Health Technology: User and Public Perspectives

Research report from Woodnewton

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# **Executive Summary**

The research was commissioned by MHRA and NICE with funding from the Wellcome Trust to explore the attitudes and experiences of current and potential users of Digital Mental Health Technology. This would in turn help them to design future regulatory and evaluation frameworks.

Woodnewton held 28 focus groups and eight depth interviews with adults, supported by desk research and interviews with 10 intermediaries such as social workers and SEND leads. In addition, we held nine focus groups with children. Fieldwork ran from November 2023 to January 2024.

For context, we discussed with participants their **experiences with mental health** treatment and support, including formal and informal diagnosis, medication, therapy, self-help and societal attitudes. Key findings included:

 While awareness of and open discussion about mental health had improved in recent years, there was still stigma, particularly towards certain conditions, amongst some communities, and in some settings – notably the workplace (though some employers were also leading on better openness and support). There was growing demand for mental health services, and capacity could not keep up, leading to long waiting times and less effective support.

- That growth was in part due to the stresses of modern life, including social media and other forms of technology.
- Unlike many physical conditions, mental health was often perceived to be very individual in terms of causes, treatment and support. The ideal was therefore an integrated package of care designed for each patient.

We asked participants about their awareness of and experience with DMHT. Around half had used apps to support their mental health, but mostly these were basic products such as mood trackers, sleep and relaxation and meditation apps. Overall:

- While awareness of DMHT was largely down to advertising and media coverage, choosing an app to try out was more driven by recommendations from family and friends.
- While some were very pleased with the products they had used, others were unimpressed with their design and functions.
- A high proportion were no longer using the products: sometimes this was because they had worked or the reasons for using it had subsided, but often because of cost or because they did not make much difference.
- Generally, participants were accepting of a 'trial and error' approach to finding apps that worked for them, particularly where they could make use of free trials or did not cost.

We asked participants about **how DMHT could best be deployed** within mental health care and support. They thought that:

- DMHT could make a valuable contribution, but the risk was they would be used to try and cover over failings in the mental health care system.
- Ideally, for the most part DMHT should be used as part of a wider treatment package, alongside regular therapy sessions and/or medication with regular reviews; though in some cases an app on its own might be all a patient needs.

- There was a case for using apps as a temporary substitute while waiting for formal diagnosis or treatment, particularly if the alternative were medication.
- The cost of apps could be a major barrier to their use, and if 'prescribed' by the NHS, they should be free at the point of use.
- If being relied on by anyone with a serious mental health condition, the apps should provide a route for users to connect rapidly to a healthcare professional to seek help. They should also alert a HCP if a user displays worrying behaviour.

Some participants (and some intermediaries working with children) were very resistant to the use of DMHT, seeing it as leading to further alienation.

#### Regulation

Participants generally found it difficult to engage on the topic of regulation. This was either because they assumed that DMHT was regulated in some way, but did not know how; or because they assumed DMHT was not regulated and, like apps generally, was more of a 'wild west'. For some participants, this was accepted as 'just how tech works'; and more also felt that DMHT did not generally pose much risk so that regulation could be limited.

The two key exceptions were data security and ensuring that any interaction with mental health professionals should

be fully regulated. Participants did not state which organisations they thought should oversee these two areas, but from the context it is likely that they would expect GDPR to be regulated by the Information Commissioner's Office and professional standards by the relevant professional bodies.

There were also some concerns about DMHT providing misleading information or diagnoses. For some this was a very serious worry, especially for children or vulnerable people. Others felt that most people would not rely solely on DMHT to diagnose and the benefits of providing some useful information outweighs risk of misdiagnosis.

They were broadly in favour of regulation, so long as it did not unduly restrict access to DMHT products. There was no support for requiring a prescription to access DMHT (though where prescriptions meant free access then they would be welcome).

Most participants did not see how self-regulation would be fully effective: developers and retailers were assumed to be more focused on profit, and some users of DMHT were particularly vulnerable to marketing, in-app purchases and data breaches.

#### **Endorsements**

Participants saw significant benefit from product endorsement (to show that they worked and were safe) and for the authorities to intervene to ban products if there were serious problems. They were very positive about the idea of a source of authoritative guidance and expressed some frustration that this was not already in place.

They had a very limited knowledge of the regulatory environment and generally spoke about 'the NHS' offering endorsements to DMHT and 'the government' banning them. When NICE and MHRA were introduced to them, they generally felt that these sounded like the right bodies to act as regulators, but still stressed the need to involve 'the NHS' given the very low public profile of the regulators.

There was support for the idea of requiring some evidence of effectiveness, on the model of clinical trials for medicines, and most participants were relaxed about anonymous data being shared with regulators to demonstrate efficacy and safety.

#### **Experiences**

Where participants had poor experiences with DMHT, they tended simply to delete the app. They might provide a negative review, but were exceedingly unlikely to complain to the app store, their HCP or a regulator. Awareness of the Yellow Card scheme was very low.

Most participants did not appreciate the potential of AI to replicate human interactions such as therapeutic discussions, mood monitoring or diagnosis. When shown examples of Al, they were surprised by its potential, though views were mixed on risks and benefits. They were particularly alarmed by chatbots that attempted to develop emotional relationships with their users.

There were some significant differences in attitude and experience by different demographic:

- Younger people, those with high educational attainment and males tended to be more positive about DMHT and AI.
- Minority ethnic participants often said that, because of stigma towards mental health in their communities, DMHT had distinct challenges but also additional potential benefits.
- Children and young people were more confident about their ability to navigate the risks in DMHT, such as online forums; but professionals working with children were most alarmed of the risks and dangers of encouraging young people to access mental health support through digital technology.

Overall, most participants were positive about DMHT and felt that it can have a positive role in supporting people with their mental health. At the same time, the general consensus was that DMHT is beneficial where:

- The products offer additional support, and are not used to replace professional help.
- Vulnerable people are properly

- protected, particularly on data and finances.
- If someone is in immediate need of help, there should be a clear pathway to get this.
- The information and guidance they offer needs to be correct, with professional involvement.

# 1. Introduction

In this chapter we set out the aims of this project and its contribution to the wider work of MHRA, NICE and the Wellcome Trust on Digital Mental Health Technology. We also describe the methodology employed, including the sample of participants.

#### 1.1 Aims

Digital Mental Health Technology (DMHT) is a broad term for products that provide information, support, monitoring, guidance, signposting, diagnosis or treatment for those with mental health conditions or challenges through a mobile phone app or other digital channel. DMHT potentially covers a wide range of products, from a simple meditation app to Al-based therapy. The sector is also characterised by rapid evolution in technology; and a rapid increase in usage. This has created new challenges for regulators in ensuring both efficacy and safety; and in communicating the potential benefits and risks of these products to healthcare professionals, to other 'intermediaries' such as social workers or teachers; and to the public.

In May 2023, the Medicines and Healthcare products Regulatory Agency (MHRA) and the National Institute for Health and Care Excellence (NICE) launched a three-year joint work programme, with funding from the Wellcome Trust. The main aim of the project is to provide guidance on appropriate, risk proportionate regulation and consistent evaluation. The impact will be access to safe and effective DMHTs to improve outcomes for people with mental health conditions.

One strand of the scoping phase of this programme was developing a better understanding of how actual or potential users perceive and experience DMHT and their expectations of how DMHT products should be regulated, if at all. Woodnewton was commissioned in September 2023 to carry out a programme of research with actual and potential users of DMHT, covering both those with a formal diagnosis and those

who had self-diagnosed a mental health condition or self-reported mental health symptoms.

#### 1.2 Method

For the research, Woodnewton adopted a qualitative approach: that is, open and exploratory discussions in small groups or one-to-one steered by a moderator or interviewer. This was best-suited to elucidating people's perceptions and experiences, particularly as DMHT is a relatively new area and many participants would not have direct experience of DMHT products and might not have thought about potential risks and benefits. This approach generated sufficient insight to meet the research objectives of the scoping phase – identifying themes, patterns, risks and benefits.

With qualitative research, there is always a question of the extent to which the findings from the sample of participants can be extrapolated to the wider population. For example, we cannot say that a certain percentage of the population hold a particular view or behave in a particular way. What we can say is that these views or behaviours are highly likely to reflect in broad terms those of the public or, in this case, those with some form of diagnosed or undiagnosed mental health condition. In the report, we have used terms such as 'some' or 'many' as a guide to the prevalence of these views or behaviours amongst participants; and also our judgement about the likely prevalence

in the wider population. Similarly, we have included verbatim comments from participants where we think these are broadly representative of people's experiences both within the research and in society more widely.

The fieldwork consisted of 33 focus groups and 20 depth interviews, supported by desk research and analysis. Participants were recruited from a database of around 500,000 UK residents who had previously indicated their willingness to take part in research, and were screened to identify those with some form of mental health concern.

The majority of the focus groups lasted around 90 minutes and were a mix of online and face-to-face, with 5-7 participants in each. In general, people open up more when they are with those they feel are like them, so we 'streamed' the majority of the groups using a range of demographic factors, such as by age, gender and social class, as well as fully mixed groups. We also ran groups where a majority of participants are from minority ethnic background, so they would feel more comfortable in talking, for example, about attitudes to mental health specific to their community. We also ran groups with participants drawn only from Scotland, Wales and Northern Ireland, to reflect differences in healthcare systems and experiences.

The depth interviews lasted around 40 minutes and were all online. The groups and interviews with children and young people tended to be shorter.

The focus groups and depth interviews both followed a semi-structured approach, in which the moderator or interviewer follows a 'topic guide' which sets out the broad themes and questions to be covered, but provides a lot of flexibility so that participants can raise points of their own and express themselves in their own words. The topic guides were informed by the desk research and also benefited from input from the working group established for the wider MHRA-NICE DMHT work programme.

The main purpose of the desk research was to inform the development of the interviews and focus groups, rather than a formal literature review. In a few cases, we have drawn on the desk research to expand on points arising from the fieldwork.

The research used a grounded theory approach with evidence rooted in participants' own experiences and interpretations. The analysis used a dynamic theory of change model to take the evidence from interviews and focus groups. This was used to explore changes in attitudes and in behaviours, including demographic subgroups where the sample size permitted. The analysis was run in parallel with the fieldwork so that findings could be fed back into the fieldwork (for example, through changes to the topic guides) to reflect emerging issues and priorities. The change model evolved during the analysis including identifying and exploring factors which would either encourage or discourage change ('drivers' and 'barriers'). The

analysis also considered the language used by participants, including comparisons and imagery, which could inform future communications and engagement.

#### **Ethics and Safeguarding**

Participants were invited to take part on the basis that they had some form of mental health concern, but it was made clear to them that they were under no obligation to share any personal information if they did not feel comfortable doing so. They were also informed that they were free to end participation at any time if they wished. They were paid an incentive to take part, to ensure a more representative sample and to maximise inclusivity. This payment was not linked to completing the interview or focus group, so would not induce someone to continue to participate when they would rather not.

# 1.3 Sample

We interviewed 184 adult participants across 30 focus group discussions and eight 1:1 depth interviews. All depth interviews and 22 of the focus groups were conducted online, with the remaining eight focus groups held in person at locations across the country. This was to ensure a good spread of participants geographically, as well as by key demographics. This research was not designed to be 'representative' of the public as a whole, or of those living with mental health conditions, but we

# Table 1: Demographic breakdown of adult participants

Undiagnosed, non-users	21
Undiagnosed, current/past	t 53
user	
Diagnosed, non-users	46
Diagnosed, current/past user	64
Female	105
Male	79
White	135
Ethnic Minority / Mixed	49
18-24	27
25-34	57
35-54	68
55+	32
England	140
Scotland	10
Wales	27
Northern Ireland	7

#### Total adult participants: 184

set minimum targets of key demographic variables so as to provide a balanced sample and to assist in data analysis.

All participants were recruited on the basis that they had mental health concerns or conditions (self-reported) and then segmented based on whether they had received medication / support

from a healthcare professional or have been diagnosed with a mental health condition ("diagnosed") or had neither ("undiagnosed"); and based on whether they currently or have ever used any software or app that helps support them with their mental health ("current/ past user") or not ("non-user"). The reasons for this approach were so that we captured the experiences of those who have used DMHT, as well as the perceptions and attitudes of those who may consider using this technology. Table 1 shows the breakdown of the profile of the adult participants in the research.

We asked participants about any diagnosed mental health conditions. The conditions they reported included: anxiety, autism, bipolar, Borderline Personality Disorder (BPD), bulimia, depression, Dissociative Identity Disorder (DID), eating disorders not otherwise specified, Generalised Anxiety Disorder (GAD), Obsessive-Compulsive Disorder (OCD), Post-Traumatic Stress Disorder (PTSD, including C-PTSD), Rejection Sensitivity Disorder (RSD) and schizophrenia.

Young people (aged under 18 years old) were also covered in the research. Two recruitment strategies were employed to recruit this sample. The first involved working with a Multi-Academy Trust to organise five in-person focus group sessions across three of its schools in England (two in the Midlands and one in Eastern England). These young people were recruited by their schools and were

not recruited based on any screening of mental health conditions or concerns (although some did have and chose to articulate in the groups discussions). In total, 35 young people (in school years 9 to 12) took part in these discussions, 21 boys and 14 girls.

In addition, we recruited a further 28 young people to take part in five online focus groups or five 1:1 depth interviews. These were recruited using the same approach as the adult focus groups, with informed consent obtained from the young person and formal consent obtained from their parent or guardian to take part in the research. All these participants were aged between 13 and 17 years; eight were boys and 16 were girls. All these participants had self-reported they had mental health conditions or concerns; and as with the adult participants, were segmented based on whether they were diagnosed or undiagnosed, and were current/past users of DMHT or not.

To provide additional insight into the role of DMHT for young people we also interviewed 10 key informants who work with young people: five children's social workers and five educational professionals working in SEND and/or safeguarding.

Combining 184 adults, 63 children and young people and 10 key informants, the total number of participants in the research was 257.

## 1.4 Mid-point Review

We designed the research to be iterative, so that the topic guides and the sample profile could be adjusted and updated based on emerging findings. Therefore, after the first half dozen focus groups we reported emerging findings to the project team at MHRA and made some minor changes to the topic guide.

We presented some initial findings to the Working group at the mid-point of the fieldwork and took the opportunity to recommend two more significant changes to the focus groups: reducing the time spent exploring wider attitudes to mental health; and adding a section on more 'potent' DMHT products.

We concluded that we had built a clear picture of the context of people's attitudes towards and experiences of mental health (covered in Chapter Two of this report). This picture largely matched our expectations, and that of the Working group members, and while this was in itself an important validation of our approach, it was agreed that this part of our research could be deprioritised. Further, part of the reason for designing the focus groups so that they began with a discussion of attitudes towards mental health was to help participants to feel comfortable with sharing their views. In practice, participants were very happy to contribute from the start, making this 'warm-up' stage unnecessary.

Most participants had some contact with DMHT in its widest sense, but

these were mainly apps providing fairly basic support, such as mood tracking, sleep, relaxation and meditation. Fewer participants had used or even heard of what we term in this report 'therapeutic' products, such as triage or diagnosis tools or AI chatbots (see 1.5 below). While this reflected the state of knowledge in the wider public, it meant we had less insight into future trends. We therefore reworked the topic guide to present participants with examples of therapeutic products along with some public concerns about them reported in the media, to stimulate further debate. In our reporting, we are clear about where the view of participants was based on their prior experience and knowledge, and where it was a reaction to the additional content we presented to them.

## 1.5 Terminology

DMHT covers a very wide range of products and there is a risk that talking about them as a single group can be misleading: people did not see an app that allowed them to record how they felt each day in the same way as an app that provided them with emotional support. Also, some participants used products which would not usually be thought of as DMHT to help manage their conditions. This gives rise to a distinction between DMHT in its narrow sense of 'digital technology designed for the treatment or support of mental health' and in its wider sense of 'digital technology used for the treatment or support of mental health'.

We have therefore adopted a taxonomy to cover different classes of DMHT, which we developed from the evidence gathered during the fieldwork. This divides DMHT in its wider sense into four types of digital products:

**Everyday:** designed for general use which could be used to help manage a mental health condition: this included task management apps, exercise apps or podcasts.

**Wellness:** designed to maintain or promote wellbeing through techniques such as meditation, sleep hygiene or managing day-to-day stress and anxiety.

**Support:** designed to support the management of a mental health condition, for example by providing information, general advice and tools. (These tools are often similar to those offered by 'wellness' products, so the differential is the way the tools are presented within the tool.)

**Therapeutic:** designed to provide diagnosis, prescription or treatment including through personal advice and forms of therapy. These may include some involvement from human healthcare professionals.

Further, participants in the research did not have a common language to describe the products or different features these products might offer: for example, the term 'chat-bot' was used by different participants to mean a simple scripted interactive feature,

or an Al-powered interface, or an Algenerated companion character. In the verbatim quotes from participants used to illustrate the report, we have not changed how individual participants have used these terms, as this is itself important evidence for future communication and engagement: but we have made clear in the context where the use of language could give rise to confusion.

## 1.6 This Report

We have used verbatim quotes from the research participants to illustrate themes in the evidence and to give a flavour of their lived experience. Each quote reveals a unique point of view and set of experiences, but have been selected to be broadly representative of the discussions as a whole, reflecting views held by a larger group of participants.

Participants often mentioned specific products and the research also presented the focus groups with examples of DMHT. The research was not intended to test the safety or efficacy of individual examples of DMHT, and so where participants criticised or endorsed specific products, this has been redacted.

Where the report uses 'we', this refers to Woodnewton and the authors, not to MHRA, NICE or the Wellcome Trust. Similarly, all analysis, conclusions and comment are to be attributed to Woodnewton.

# 2. Attitudes to Mental Health

In this chapter we report the experiences of participants relating to mental health, including the attitudes of society, the process of diagnosis and the treatment and support available to them. This sets the context for how participants thought about DMHT, including perceptions of different products and the need for regulation.

#### 2.1 Attitudes

Most participants thought that, overall, attitudes towards mental health had improved in recent years. People were more open to talking about mental health generally, and to some extent discussing their own experiences. Men, in particular, felt that it has become easier, and more socially acceptable, for them to talk about their mental health. Overall, stigma had reduced. Several participants credited celebrities such as Ant and Dec and coverage of the media for much of this advance.

However, there was also a widespread view that this improvement was not

uniform. A significant number felt that those with mental health challenges would still face prejudice and outright discrimination in the workplace. While some employers were making a positive contribution, others were only paying 'lip service' to ideas of tolerance and inclusion.

"In my workplace, we have mental health kind of safety officers where people are trained, which is really helpful. And I think people are taking it more seriously. They're realising the knock-on effects it has on physical health, so they kind of almost have now combined the two."

"They say the right thing and there are more posters up, but the pressure is still there and if you're struggling it's still a negative."

There was also a view that some conditions were still the subject of prejudice and stigma: those cited included personality disorders, psychosis, PTSD and body dysmorphia, with ignorance and fear playing a part.

There could be ignorance even within the health system, and also horror stories and media portrayals of some mental health conditions.

There were also perceived differences in attitudes and experiences by a range of demographic characteristics, including ethnicity, social class, gender and age.

"Well-known personalities have declared things like depression and bipolar so it makes it more OK to talk about them, but other conditions are less understood."

"There are some employment areas where if you're diagnosed with depression or other mental health issue you might lose your job, like the driving profession."

## 2.2 Diagnosis

We asked participants about the role of a formal diagnosis in mental health so we could better understand the extent to which DMHT technology might be used as a path to a formal diagnosis by a healthcare professional, or even as a means to avoid a formal diagnosis altogether. Some participants made the point that obtaining a diagnosis was not always easy. It might involve a wait of months or even years for an assessment; and often conditions were hard to diagnose. Several participants felt they had been misdiagnosed in the past.

Participants had a range of views about

the benefits and drawbacks of a formal diagnosis. For some, it was a practical or even an essential stage on the road to treatment and support. Others felt it was beneficial overall, but brought with it some significant challenges, including confidentiality and self-stigma.

"It helped me in understanding why my mind was turning against me."

"It depends on the condition and outcome. If you were diagnosed with something it could impact on your work or workplace, like getting promoted or keeping a job."

Some felt a diagnosis would add little or nothing to their own understanding of their condition. But even when they held strong views about their own situation, participants recognised that others would have a different take and no one was critical of others for choosing to seek a diagnosis or not. Some participants also suggested that the role of a diagnosis, and its reliability, would depend on the condition: with anxiety or depression, people could self-diagnose and self-treat. But personality disorders needed a professional diagnosis.

The main benefits of a diagnosis were seen as information; reassurance; and access to treatment and support. A diagnosis would help a patient to be better informed about their condition and about options for treatment and support, including self-management. Some expressed this as the diagnosis helping to bring into focus feelings

of 'difference' they had held perhaps for their whole lives. There was also a significant emotional reassurance for several participants in realising they were not 'alone', but faced challenges which many other people shared. Even if they did not join patient networks or self-help groups, there was a benefit from removing a source of anxiety.

"Is it necessary? I'm not sure, but I'm glad I had one. I was doing OK but I felt a barrier. But it's also bitter-sweet to know I have this."

There was extensive discussion about self-diagnosis. For some, it was a source of concern.

"I think people are making too many self-diagnoses in society. I believe this is partly due to the abundance of available information. People read something and immediately think, "Oh, that sounds like me! I must have that condition." However, I don't think it's that simple."

Self-diagnosis could trivialise serious conditions if anyone could decide that this applied to them, outside a professional diagnosis.

"A lot of people like to label themselves with it, and they define themselves especially on social media (but they have just self-diagnosed), like on ADHD."

"Young people are identifying because they have seen a [short film on social media] and this is how they are presenting to the world – ADHD, autism, bi-polar."

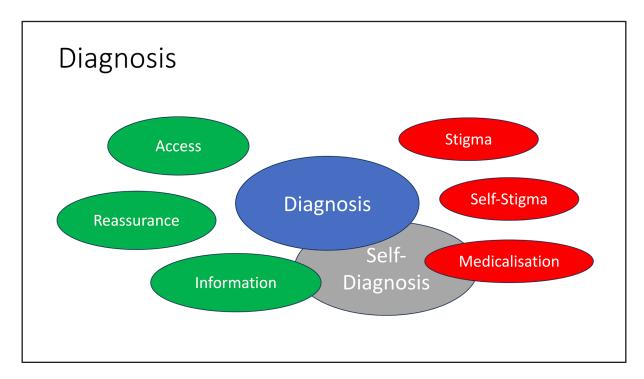


Figure 1. Perceptions of the benefits and disbenefits of diagnosis and self-diagnosis.

But many participants thought self-diagnosis was, or could be, a positive process. It enabled people to understand their conditions more fully and to take the next step towards seeking formal diagnosis and treatment, or dealing with their situation through self-help and support.

#### 2.3 Treatment

We asked participants about their attitudes towards, and experiences of, three types of treatment: medication, talking therapy, and self-help. This was intended to help us understand better how DMHT might be seen to fit within the existing treatment landscape.

#### Medication

Participants in the research were not required to disclose whether they were using any medicines to treat or manage their conditions, though some did so. It is likely that between a quarter and a third of participants were either taking medication or had done so in the past. There were mixed views about its efficacy and safety. Some reported very positive outcomes.

For others, medication had not been very effective or the adverse effects outweighed any benefits. There were also fears associated with taking medication, including becoming dependent or changed behaviour.

"I was worried about the potential side effects in the leaflet. I have a three-

## year old daughter. It's mum-guilt. I worried about shouting at her."

Some had found medication helpful to begin with, but those benefits had fallen away.

# "I don't think the tablets are helping any more."

Participants in general thought that people should be offered alternatives such as therapy so that no-one felt compelled to take medication. Some thought that doctors, and in particular under-pressure GPs, were sometimes too quick to resort to prescribing medication.

## "Sometimes it's forced on you at the start when it wasn't right for me – I was on it for five years when I shouldn't have been."

Interestingly, participants were as a whole very open-minded about the use of medication, even when they had themselves had bad experiences. There was a strong sense that everyone's treatment was personal to them, and that people should not be judged for the choices they made. This may not be representative of the public as a whole, who may not have the same lived experience of either taking medication for a mental health condition or considering doing so. This may imply that the potential users of DMHT would not like to see access to these products limited, either for themselves or for others.

## **Therapy**

Overall, more participants were positive about talking therapies. The relationship with a therapist could bring several benefits. They would be in the hands of a trained professional who ideally, would have time to get to know them and their personal situation; the therapy itself would be personalised; it would pick up on trends and behaviour patterns in the patient; and it could provide an element of constructive challenge and motivation.

"It was really helpful for me as I lack serious motivation to do anything [day to day tasks] – getting prodded into action helps."

Therapy was frequently seen as more likely to address the root causes of a condition, compared to medication or self-help. Some did report that therapy did not work for them; but this was not framed as a failure of therapy as a technique, but a reflection of the differences and preferences of each individual.

"I had six counselling sessions by phone. It didn't do it for me. I went back to self-help."

Few reported any concerns about safety, though some did say that therapy was anything but an easy option.

"It can bring back old memories and can open old wounds as well as it can normalise things and can help. It's not for everyone and depends what

# you're going there for and for some conditions it's not appropriate."

The main dissatisfactions were the difficulty of accessing therapy (both being denied access and also waiting times even after a referral), and its quality. A significant number of participants believed they would benefit from therapy in the form of an extended relationship with a qualified therapist, but that it was not available to them through the NHS and the cost of private treatment was out of their reach.

Several participants linked these two concerns by saying they had been given a short course of therapy, either by the NHS or through their employer, which was inadequate.

#### Self Help

There was broad consensus that selfhelp was an essential part of managing a mental health condition or maintaining mental health. Participants offered a range of self-help tools and techniques, ranging from yoga to pets.

"I went to the gym and had a personal trainer. It was like therapy. You could tell he was entirely listening to me."

But some participants said how difficult it was to find the right tools or approaches on your own. Also, self-help depended on recognising that there was a problem; and giving it priority amongst other competing demands.

"I have to be responsible for people

– wife, kids and people at work. I feel
like therapy is not on the radar."

Participants emphasised that self-help could be most difficult when it was most needed: that is, when people were struggling with their mental health, the energy and commitment to pursue self-help could be most difficult to achieve. This was seen as a significant limit on self-help, and also underlined why self-help worked best when integrated with other forms of support, or as a means of maintaining mental wellbeing, rather than as a tool to address mental ill-health.

## 2.4 Support

There were three main themes to the discussions on support for mental health within the health and care system.

First, the need for integrated support.

This would involve health and care services, along with families, friends and employers, and also the integration of different forms of treatment, therapy and support, of which DMHT could be one strand.

Second, the need for support to be tailored to the needs, circumstances and preferences of each individual. So while integrated support was the ideal, this would look different for each person – for example, whether they were in the workplace or not, or whether they wanted friends and family to be involved in their treatment and support.

"I'd rather talk to a stranger. Family can be a burden."

The third was capacity within the system, which was generally seen to have either failed to keep up with rising demand, or even to have declined.

"There's no long term care unless you are at an absolute crisis point."

"Nineteen years ago when I first had my first breakdown, I was seen in a week."

This context – the various treatments and forms of support available to mental health, as well as views on mental health itself – proved to be fundamental to how participants approached the subject of digital mental health technology.

# 3. Perceptions of DMHT

In this chapter we report on how participants thought about DMHT, including their awareness of DMHT products and their capabilities, the extent to which they were interested or not in using such products, and their perceptions of the positives and negatives of their use in a range of contexts. We also introduce the concept of 'potency'.

#### 3.1 Awareness

We asked participants for their associations with the term 'digital mental health'. Some linked it to apps to support mental health; others saw it in terms of problems caused by digital products, such as addiction, 'endless scrolling' or losing track of time. Some saw it as both.

Very few participants recognised the term 'Digital Mental Health Technology'. Most were comfortable with the term 'mental health apps', even if they had not come across it before. However,

participants did not always have a clear view of what the term 'mental health apps' would cover.

There was a widespread view that it was very hard to access mental health services due to barriers of cost and capacity. This meant that apps - seen by most as relatively cheap and instant were potentially of great value. The other driver was convenience, because the apps could be accessed at any time from a device that most people had with them constantly. Anonymity was also mentioned fairly often in the context of feeling more confident using an app than speaking to a healthcare professional, though participants sometimes thought this would be a positive for others, not for them personally.

In general, participants were much more aware of (and had more direct experience of) apps intended to promote well-being in its widest sense, such as reducing stress and anxiety, promoting mindfulness and wellbeing, and encouraging healthy lifestyles. Much of the discussion in this section

therefore reflects their views about these less ambitious or 'potent' products. For example, even when positive about these kinds of products, participants often stressed that there were limits to what they could achieve: that they could not 'cure' or manage 'serious' mental health conditions.

in the research were only positive. They could be positive overall, but with reservations or qualifications. For example, a common theme was that DMHT could be very helpful, but as a supplement not a replacement for other forms of treatment and support.

#### 3.2 Perceived Positives

A clear majority of participants thought that DMHT in its widest sense had the potential to make a positive contribution to mental health support. In part, this was based on their own experience with using apps such as those for tracking mood, providing mindfulness exercises or coping strategies or other forms of advice and support. Many participants reported positive experiences with mindfulness and wellness apps, often alongside other forms of support or self-help such as outdoor exercise. YouTube and TikTok were also mentioned as providing advice, support and motivation, and (along with podcasts) as providing meditation and other material which could help manage people's moods.

For most participants, the main benefits were seen to be the accessibility and convenience associated with the mobile phone platform. (Although a few participants had some experience of DMHT which used a computer, the majority had mobile apps in mind throughout.) Other positives included choice, privacy and quality: but it is important to note that few participants

#### Access

One of main attractions of DMHT is the idea that it could be made available to everyone who wants or needs it. This was a direct response to perceived or actual capacity and access problems with mental health services we saw in Chapter Two.

"You can't get through to the GP. You see the nurse, but they can't prescribe or diagnose."

"They definitely have their place.
There are lots of gaps in the service."

Apps could also form a half-way house between suffering alone and a formal approach to a health-care professional. They might explore why they feel the way they do, and how they might help themselves, before approaching a healthcare professional; or it might form a 'stepping-stone' on the way to more formal care.

"If I was too scared to get help and wanted an initial assessment it might help... and then encourage you to see a healthcare professional."

Some participants were wary of approaching healthcare professionals: for example because they might have to reveal this later to an employer, or because it might turn into a child protection issue.

"It can be hard to open up to the doctor. There's only so much you can tell them. What about if you have kids? Will they say you're unfit to look after them?"

Participants felt that some people would not want to have to access DMHT through a therapist or other HCP. Freedom of choice is important, including the choice not to seek help from a HCP (and that the healthcare system should not prevent someone from having access to an app).

"Before COVID I had never thought about doing something like this because I was not comfortable with it. But obviously it was the only way to communicate. So, lockdown broke down a few boundaries."

Nevertheless, a clear majority of participants felt that healthcare professionals should be involved in prescribing and recommending mental health apps. The key benefits are that DMHT would then be more likely to be integrated into their wider care; and the assumption that the specific product will have been checked or approved and will be more appropriate for them.

#### Convenience

A key benefit of DMHT was that it could be accessed at any time. There were no waiting lists or booked hours, no limit on the time they could spend with the product, compared to a short consultation with a GP or even a 50 minute session once a fortnight with a therapist. Also, it did not need a separate device or channel, but could be accessed through a mobile phone, which almost all participants had with them almost all the time. This made it easier for users to fit it around the rest of their lives.

"I've been recommended CBT – never did it – too much effort. If I had an app it might be easier to do it."

A few participants linked this convenience to the challenge of making time for self-care: when they faced competing demands on their time, some formal activities like exercise routines might go by default, but an app could be used in spare moments and so provide at least some limited support. This flexibility was also helpful in the workplace.

#### Choice

Participants saw DMHT as providing extra choices. There were usually a range of apps for different tasks (recording mood, meditation and so on) and they could try different ones until they found one that suited them best. They could also choose when, where and how much

to use the app, whereas other forms of treatment or self-help might be limited and also provided in a fixed format (such as a weekly therapy session). Apps also gave them the option of gaining support outside the formal relationship with a doctor or therapist.

#### **Privacy**

Participants saw privacy in two dimensions. DMHT could in some circumstances provide greater privacy than the alternatives, for example because it would not require a formal diagnosis which might have to be disclosed to an employer; or because it would not require booked sessions with a therapist.

"I have a friend in the Army who would lose their job if they sought professional help, so we need these apps."

Participants felt it was important that the use of DMHT could remain private, for example in how the app was branded, whether it could be hidden on the phone's home screen, or in the use of alerts and pop-ups. It helped that many apps presented themselves as about 'wellbeing' rather than designed to treat a mental health condition.

"You can hide the app on your phone so that others can't see it."

"I'd be very worried in my culture if anyone saw it."

"I had a baby centre app on my phone

so I hid it, as I didn't want people to know I was pregnant!"

"They'd have to be subtle. You wouldn't want to call it 'lamdepressed. com'."

#### Quality

A few participants expressed frustrations with the nature or quality of the support they received – or expected to receive – from the healthcare system, either because HCPs did not have the time to listen to them properly or because their responses were not appropriate. This led them to see apps as a better alternative.

"I'd definitely prefer to use an app.
When I have been to the GP previously
it's been: "Do you want a sick note?"
And I'm like: "Well, no, because I'm
not sick. I'm quite able to participate
in day-to-day life. I just want some
support."

## 3.3 Perceived Negatives

#### **Digital**

A significant number of participants were strongly against the whole idea of DMHT, either because they themselves would not want to use it, or because of perceived wider harm to others or to society.

"It's insanity to use the thing that's causing the problem as the solution."

Some felt that spending more time on digital platforms or looking at screens would be bad for people's mental health. Others went further, saying that social media in particular was a major cause of mental ill health and it was perverse to see DMHT as the answer. People should be encouraged to spend less time online and more time in the 'real world'.

"I'm sceptical and not convinced that the answer to good mental health lies in apps and digital technology - I think tech is causing or exacerbating mental health issues."

It may be significant that while participants were generally open to others making choices about mental health that they themselves did not agree with – for example, on taking medication – on this there was more of a sense that those opposed to DMHT would be against it being promoted to others.

#### **Exploitation**

A significant number of participants resented the idea of businesses 'making money' out of people with mental health conditions. They felt that this was unfair in itself; and also meant that the products could not be trusted as far as they should be, because the way they were designed and marketed would be focused on maximising products, not the best interests of the user. Not all of those who held this view thought this would stop them using an app; but it would make them more cautious or suspicious.

As we will see, this strong negative perception influenced their views in other areas of the research.

#### Impersonal / Generic

Participants also held the view that many DMHT products were too generic, in that they were designed for general use and did not directly address their condition or their individual needs. Some also commented that they would prefer apps that bundled different tools or features together in one package, rather than having to download and learn to use a range of apps. This would allow them to choose the features and support that suited them best.

#### Motivation

This was a major issue for those with some experience of using DMHT. Several participants commented that they had been surprised by the poor design of the apps they had used. They were unengaging and easy to give up on. (This was a concern which also came through clearly in the desk research.) Several participants said that the apps did not recognise the barrier that mental health conditions could create in terms of motivation and engagement, and that this could form a major limit on the effectiveness of DMHT, compared for example to traditional therapy. Others thought that apps could be made much more engaging, including through personalisation, motivational tools and gamification.

"You need to be held accountable on an app. A therapist will ask you to do homework."

However, it was also a concern that some of these motivational techniques could also bring greater risks in areas such as anxiety, over-use and dependency. Some participants felt that monitoring apps could be problematic because it gave them something to check frequently – for example, heart rate as a sign of anxiety – and any negative readings would worry them. Some made a comparison to the anxiety caused by 'Googling' physical symptoms.

#### Dependency

A few participants expressed concerns that they could become dependent on apps. In some cases these were linked to typical negative app-related behaviours such as 'death-scrolling" and "rabbit holes", but were also about the products themselves.

"Everyone has mental health challenges – what makes us different is ability to manage it. If I'm struggling a bit I don't want to become dependent on an app."

Some participants noted that commercial app providers would have little or no incentive to 'cure' their users, as this might mean they would lose subscribers and revenue.

"I'm quite cynical – does the app want you to be better? It wants to keep you ill to keep you engaged. It feels like a Black Mirror episode."

#### Security

Some participants expressed concerns about whether DMHT products would be secure, particularly given the sensitive personal information they would gather and retain. Some said this would put them off using them entirely, but a more common view was that so long as they were properly reassured about data security, they would be prepared to use the products.

"I'd be worried about being monitored all the time – they will be tracking everything and can it be misused?"

"You could lose your job on mental health grounds. So a leak would be awful."

#### Quality

Participants did not always have high expectations of DMHT in terms of quality and useability. Some had used DMHT apps which were not user-friendly or lacked relevant or appropriate content, or were otherwise poorly designed. Others may have had their impressions of DMHT shaped negatively by experiences with other kinds of apps.

"I have a CBT app on my phone but it only works because I had real CBT. Without that, the app would be no use. It's basic and boring."

#### Cost

Cost was one of the most widely-held negative views, particularly amongst those who had used DMHT. This included:

- Resentment that those who needed these products would have to pay for them.
- A sense amongst some that the products they had used or tried did not offer good value for money.
- Suspicion that products were designed to maximise revenue, not to maximise the benefits for users.
- The subscription model, in which you never actually owned the product and were vulnerable to it increasing in price or the manufacturer not investing in it. 'Subscription equals dependency.'

Finally, there was a general view that the NHS should only recommend apps if they are free at the point of use.

#### Risk

When asked about the risks DMHT might offer, or groups who might be particularly vulnerable, the main concern was about the products being digital, which could make problems like alienation more severe (see 'Digital' above). Participants also mentioned the risks of self-diagnosis, negative digital behaviours such as 'doom-scrolling' and the vulnerability of children and young people.

Although listed here as a negative, in general participants did not see these products as 'risky'.

"It's not like it can do any damage – except you might not seek further help."

This perception is likely to arise from the fact that the experience of most participants was with apps which had modest aims. If people had more direct experience of more 'potent' apps – for example, offering diagnoses or providing therapy – their perception of risk might change considerably.

#### 3.4 Overall Views

It is important to emphasise that each participant often held multiple and sometimes overlapping or even conflicting views. For example, a participant might both see the potential of new technology and also have deep reservations about it.

"I had a health app for my dog. The vet could look through the camera into his ear and check that it was OK. It saved me a trip to the vet. But actually my dog died of it."

People also saw DMHT having the potential to make a valuable contribution, but one which might be limited.

"I think if you're wanting to deal with... the presenting issues of a condition on a day-to-day basis, then an app would be really useful. But if you really want to change the underlying thought processes and feelings, then I think that's where you need a real person."

#### Diagnosis

The idea of being diagnosed by an appraised strong concerns from a majority of participants. Some thought it could be appropriate if there were sufficient safeguards, but most felt that this should be left to healthcare professionals.

"I worry about getting the diagnosis wrong and this could make the symptoms worse. You need tools to help you, but not to diagnose you. This needs to be in-person: this is critical for a diagnosis."

Some participants said that mental health diagnosis was very different from physical diagnosis: much more nuanced and personal, with a unique set of causes and a need for a tailored treatment package.

"Mental health diagnosis is not the same as physical. It needs a professional who can pull out the nuance and often multiple things. Treatment for a broken arm is the same for everyone, but treatment for a mental health condition will be different for different people."

These reservations applied even more strongly to apps offering self-diagnosis.

"I wouldn't want to go on [an app] to diagnose myself. I wouldn't trust it

to give the right diagnosis, especially from AI."

Some participants thought that diagnosis through a properly-designed app would be preferable to 'googling' symptoms or conditions as it would be more personalised and could also offer some reassurance. Yet even where participants were broadly positive about DMHT, they tended to be more cautious about diagnosis.

"With diagnosing, maybe it needs to be more careful [...] I should not be able to diagnose myself with bipolar. I'd be concerned if you have a question tick-box and it gives you a diagnosis. Mental health is incredibly nuanced)."

#### Safety

In general, participants did not perceive DMHT as posing significant safety concerns; but some did see risks, particularly around misdiagnosis and making conditions worse.

"I'd worry they'd tell you too much – if you're on a downer they are going to make you worse."

But safety was also seen in terms of the alternatives, where an app was 'safer' than prescribing medication or doing nothing.

"I think apps are likely to be safer than the range of side effects present in many meds."

#### Scope

Participants often had their own interpretation of what might constitute DMHT or what digital products could be adapted to support their mental health. They also saw the scope as extending to include areas such as addiction and isolation, meaning that apps to support dieting, giving up alcohol or drugs or even dating apps could be part of their own DMHT landscape, even if they did not think it should be formally covered by the definition.

"I've used an app to help stay sober – it's for meeting other people who don't want to drink socially, a kind of Tinder for sober people. Maybe there could be something like that for loneliness."

# 4. Experiences of DMHT

In this section we consider the views of participants who had direct experience of using DMHT and other digital products to help manage their mental health or to diagnose or treat mental health conditions. It includes how they selected these products, positive and negative experiences, and examples of where they were no longer using them. It also covers how participants reacted to three examples illustrating how DMHT could offer self-referral, triage and diagnosis and also employ Artificial Intelligence.

## 4.1 Choosing a DMHT Product

Participants saw a range of difficulties in choosing DMHT products, particularly if there was not the option of a free trial. Without some form of advice or guidance, it would be hard to select the right product.

"I google everything. You might get

the answer that you want, but then it could give you unnecessary products and you'd download apps you don't need. You can only know how useful the app is once you have tried it. With some apps you won't get access to much until you have paid for it."

Participants mentioned a range of sources of advice or recommendations which they had either used in selecting a DMHT product or might consider using, based on how they made other similar decisions.

#### **Advertising**

Almost all participants expressed caution, or even downright cynicism, about advertising, including on social media. Partly this reflects how people say they react to advertising generally: but there is some unease about companies making money when people "are vulnerable". This extended to star ratings and positive user endorsements.

#### **Employers**

A significant number of participants had been provided with or recommended DMHT by their employer, and in general were positive about this. There was an expectation that this would if anything increase as the need for workplace wellbeing and mental health support grew and employers became more involved in meeting this need.

#### Family and Friends

In general, participants were positive about seeking advice or recommendations from family and friends: these were both trusted sources and also knew the individual well and would be a good judge of what would work best for them. However, not everyone would use this route, particularly because they would want their concerns to remain confidential.

"I'm more likely to try something if it's recommended by friends or family than a healthcare professional because they would have used it and I know it's a real thing."

#### **Forums**

Participants had mixed views about using a discussion forum to help make their choice of DMHT. Some felt it would be helpful to hear from actual users; others felt they might be drawn down 'rabbitholes'. Most participants appeared to have made little or no use of forums, and so did not have a view. Young people

were more likely to have used forums and to be most confident about their use: they tended to be aware of the risks (for example, being encouraged to explore negative behaviours) but felt they could recognise and avoid these.

#### Influencers and Content Providers

Some participants mentioned influencers and content providers on platforms such as YouTube and TikTok as a source of information and/or recommendations. They tended to distinguish between those who were clearly promoting DMHT products for financial reasons, and those who had a genuine connection to the subject-matter of mental health and/or had used the product themselves. They thought the former would not be likely to influence their behaviour, but the latter would be a strong endorsement, particularly if they already followed that content provider or relied on their content.

# "I found the [media personality] app through social media feeds. She has such a good reputation."

A number of participants recalled adverts for DMHT, on social media and elsewhere, including on tube trains in London and some commented on how intensively some products were being promoted through social media channels and on podcasts. (Only a few thought that these ads were likely to change their behaviour, but it may be that there is a social acceptability bias against admitting to being influenced in this way.)

#### **Reviews**

Participants were frequently cynical about reviews and star ratings, seeing them as being open to abuse, for example with 'paid-for' reviews. They often had 'strategies' such as looking at multiple reviews or ranking reviews from newest to oldest, so they could find reviews they could trust. Participants said they would trust a personal recommendation more than an advert, and an endorsement from a doctor more than one from a celebrity. They would be encouraged to use a product if they saw it had been developed by or with mental health professionals.

#### **Schools**

These were a very important source of information and advice for young people (see Chapter 7), including directly providing access to apps and other resources. They were also significant in helping adults to understand more about mental health and about DMHT.

#### **Wellbeing Providers**

Some participants had been recommended DMHT apps by those working in the wellbeing or exercise sectors, such as yoga teachers and personal coaches. This was seen as helpful, though having some of the same limitations as family and friends, including the extent to which an app that suited one person would work for another. There was also some concern that wellbeing providers might be

incentivised to recommend specific products, much like influencers.

## 4.2 Products and Uses

As part of the research, we asked participants about the DMHT products they had used or heard about. The project was not intended to assess the efficacy or safety of any specific DMHT product but where participants cited specific products to illustrate the points they were making, we have included that in our reporting. Where participants are positive or negative about specific products, this does not reflect the views of Woodnewton or of the project sponsors. Typical comments included:

"[meditation app] sometimes helps me get out of an anxiety spiral. At the end of the working day, it helps me let go of the work. It's not hugely life changing, but helpful."

"I have [breathing app] to help deal with panic attacks."

"I use [meditation app] before a stressful situation I know I'm going to face, like an interview or presentation. It's really helpful."

One clear pattern was that both use and awareness varied by product type. Some categories of DMHT (used in its wider sense of products used to support mental health, as opposed to those

designed for this purpose) were much more frequently cited than others. This included mindfulness, calmness and meditation apps. From this, we were able to develop a broad taxonomy for DMHT covering four groups of products: 'everyday', 'wellness', 'support' and 'therapeutic'.

Another pattern was that – as we would expect – more people were aware of DMHT than had tried it, and those who had tried it outnumbered those who had adopted it. A significant number of people had tried to adopt DMHT but were no longer using it for a range of reasons, meaning the number still using it was only a fraction of those aware of DMHT.

Adding in the relatively low awareness or and experience with DMHT offering

'therapeutic' support (such as diagnosis or therapy), the difference between awareness of DMHT and use of the products which offered the highest risks and rewards was dramatic.

One of the clear findings from the research was that an app might work well for one user and not for another.

"Another I've used is [sleep app]. It involves creating a mental image or listening to sounds that promote a sense of tranquillity. For example, you can imagine yourself in a cozy room with rain pouring heavily on the roof. By picturing yourself in this environment and immersing yourself in the sound of the rain, you can transport your mind to a peaceful place."

Another participant in the same group

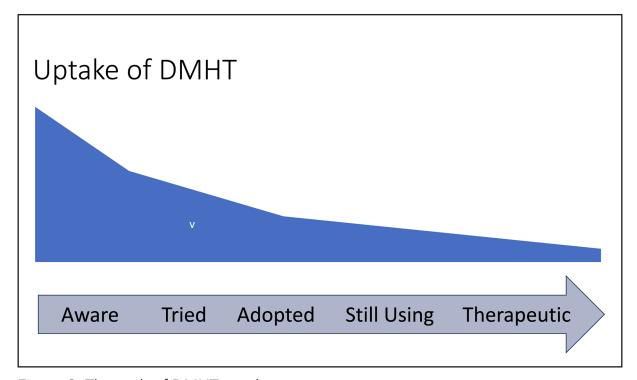


Figure 2: The path of DMHT uptake.

had found the same product unhelpful.

"It had a feature that tracked how often you used the app and the specific activities you did. This actually made me feel more anxious, as it created a sense of dependency on the app."

In general, participants felt strongly that it was important for there to be a choice of apps, so that people could find the one that worked best for them. This reflected their belief that mental health was very personal and often complex.

#### 4.3 Positives

Participants had positive experiences using apps for self-help, mindfulness, and tracking mood and symptoms. Some

participants found digital apps helpful in managing stress and anxiety.

"With [meditation app], you can do mindfulness groups and webinars. It's working well for me apart from the expense. If there is a problem, you can tell the therapist."

"I use this [tracker app] for an eating disorder, but it can be used for anything. You record how many days you go without relapsing. It's useful for monitoring and motivating you. I stopped using it because I recovered, but I would recommend it to other people..."

"When I was referred for counselling, [non-NHS health provider] had inhouse tools on their website. You fill in your mood and have workbooks to go

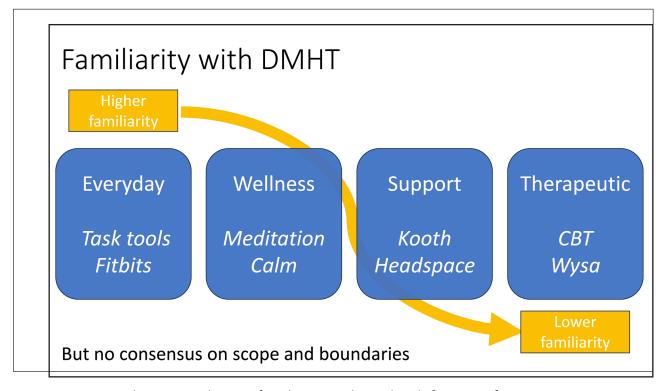


Figure 3: Schema combining familiarity with 'wide' definition of DMHT.

through. It's fine as a standalone, but not a replacement for counselling. I needed someone to talk to."

#### 4.4 Negatives

Many participants who had experience of DMHT apps expressed disappointment and frustration about their design and quality.

"I have [health support app] from work. I can't work it out – the font's too small, it asks too many questions. I've been promised loads of help but it's too hard to work through."

"I used [mental health support app] but I didn't enjoy it. It was supposed to be AI-powered well-being check-in but it was really superficial."

For some, the lack of human engagement appeared to be part of the problem:

"I had a portal for CBT and I felt like it was homework – I ended up just filling it out to show I was doing it rather than doing it for the right reason."

As with self-help, there was a theme throughout the discussions of needing both self-awareness and self-motivation to get the most out of DMHT, and not everyone has these – particularly when facing challenges with their mental health.

"I have [mental health support app] through my employer, but you need selfknowledge to make proper use of them."

#### 4.5 Discontinuing Use

A significant number of participants had experience of specific DMHT products and then stopped using them.

"I tried one [mood app] but it just gives notifications. I just deleted it. It was not for me. There was no human contact."

This was for a range of reasons, and was not always because of any perceived failing in the product itself. Sometimes it was because the product had 'worked'.

"[mental health community app] helped me. I don't use it anymore as I now do more meditation which is more helpful to me."

Cost could be a factor. A significant number of participants had taken up free trial offers and in many cases found the product to work well, but were not able to continue to pay for it.

"I couldn't afford it anymore, so I just stopped using it."

In at least one case the product was no longer available, which raises the question of potential negative impact on users, particularly for more 'potent' products.

"I've been using an [mental health support app] for a long time – unfortunately it's been withdrawn from the UK market. It was a nice little friendly robot who asked how I was doing." Some participants said that the reason they did not benefit from or continue to use DMHT was not the fault of the product, but their own preferences or commitment.

"I tried using an app for journaling, but I didn't keep it up. But I don't like journaling on paper either."

The high number of participants who said they had stopped using a DMHT product was reflected in the desk research, which showed disengagement and discontinuation to be widespread. In some cases, participants simply tried an alternative: in other cases, they gave up on DMHT altogether.

Significantly, no participants reported that the use of DMHT had caused them harm. A few thought it had made their symptoms worse (for example, not completing a journaling app making them feel anxious) but they had dealt with this by stopping use of the app. The main harms they thought the products might cause to them or to others would be to lead people down a self-help route when they needed more intensive help and support, with serious conditions potentially going undiagnosed or untreated.

#### 4.6 Features

We asked participants about different features that DMHT could offer. In general, they felt that the more functions the better; though there were also some concerns.

#### Diagnosis

Participants were typically very negative and suspicious about the idea of DMHT providing a formal diagnosis. This was felt to be the preserve of a healthcare professional. The one exception was where DMHT might provide an initial triage or an informal diagnosis which might lead the user to seek professional advice: but even here, there were concerns.

"An app can only go so far. It can't give you a precise diagnosis and there is a danger of wrong diagnosis."

#### **Forums**

Participants were generally positive about the inclusion of forums or other ways for users of DMHT to connect and share experiences and advice. However, some did have doubts about the safety of forums, and professionals expressed considerable concerns. Some made the comparison with other apps, for example one that allowed the user to find other young mothers locally: this had turned into a 'brilliant' support group. But forums were not seen as a substitute for real-world support groups – more a supplement or a way for groups to get started.

"Anonymous views from others would be valuable – as well as techniques that can help you think about things."

Some felt forums would need to be supervised by the DMHT provider, particularly as users would be vulnerable

and could be affected by negative comments or unsuitable advice. This implied the involvement of mental health professionals, as there should be a way for those exhibiting concerning thoughts or behaviour to be identified and offered support.

"I used it as a well-being score and the professional reviewed it in our one-toone sessions."

"They should have monitoring for key words. You could have the encouragement of self-harm or other bad intent."

#### Gamification

In part because of the wider feeling that many apps were unengaging or badly designed, leading to high dropout levels, some participants felt that gamification elements in apps like Finch could make self-care activities more engaging and enjoyable, helping users to stay committed. Others found gamification off-putting, and there was some concern about apps having 'locked content' which users would need to complete tasks to access as this could trivialise mental health.

#### **Tracking**

Most participants could see the benefit of being able to track mood or behaviour; although there were some concerns – including from users – about the risk of tracking creating anxiety or a sense of failure. Again, the ideal was seen to be DMHT apps used within a supervised treatment plan, in which targets or tracking could be used appropriately and safely.

## 5. DMHT and Healthcare

In this chapter we report on how participants thought that DMHT could best be deployed within the wider healthcare system, including questions of how they might choose a product, the features they might like to see included, the extent to which DMHT could be integrated into or even replace some mental health services, and the way the technology might evolve, including the use of Artificial Intelligence (AI).

#### 5.1 Recommendation

Participants were in general quite suspicious of the manufacturers or distributors of DMHT: their prime motive was profit, not the interests of the user. They also saw the need to match their individual circumstances and preferences against a range of potential products. This made some form of independent recommendation and endorsement important to them.

"My app is attached to my gym and it always recommends going to the gym!"

"It depends on the motivation of the app and what advice they give – are you directing me to products and services they provide? If it's done in association with a mental health charity and had some trust then it would have more credibility."

Most participants thought that they would use DMHT if it were recommended by a healthcare professional.

"They are professionals and so if they are recommending it then I would generally do it."

But there were some reservations. A few participants thought that some HCPs might have a financial incentive to recommend a particular app. Others thought that some HCPs would recommend apps to ease their own workload, even if this were not the best outcome for the patient. This might be one reason why a broader NHS endorsement was often seen as the ideal: it would have the credibility of healthcare professionals, but without the potential risks of an individual HCP's

personal views or prejudices.

"I have the patient access app and if they recommend one then it would be powerful. Same for the NHS app."

Some also saw a role for medical charities.

"Does [mental health charity] have an app? If they had one, I might be more inclined to pay them than a private company."

#### 5.2 Integration

Participants had strong doubts about stand-alone apps offering therapy or other forms of treatment, particularly for more serious or risky conditions. They sensed this was about cost and lack of capacity rather than what works best for the patient.

"There's something about sitting in a calming room with someone else, outside your home. Empathy is really important – you don't get this from an app."

They felt strongly that digital tools should be integrated into the overall treatment plan and used as a complement to face-to-face therapy. This would also help free up HCPs to concentrate on the more serious cases and/or where they could add most value. Participants could also see some of the implications for the health system. These included:

- The potential benefits of the integration of digital mental health tools with electronic health records.
- The need for technology integration to be accompanied by proper training for healthcare professionals.

"It would help if the counsellor or GP was able to look at your app to review when they see you or review it and give you some advice."

#### 5.3 Monitoring

Several participants said that DHMT should allow healthcare professionals to monitor their use, so they could understand the user's situation more fully, or even intervene if there were causes for concern. This linked back to concerns on data security and privacy and while there was a wide range of views expressed in the discussion, there were some areas of broad agreement:

- It should be an option for a user to share their data with others, such as a therapist or informal carer, so they can provide this oversight and support;
- It could be valuable to extend this to healthcare professionals, though there were doubts that the NHS would have the capacity to act rapidly on any warnings;
- It was acceptable for anonymised data to be shared with academic researchers or with a regulatory body to evaluate how well the apps

worked;

 It would not be appropriate for data to be shared more widely, for example with advertisers, even with consent, given the vulnerability of those using the apps.

"I think, for me, it's important for them to track your process, track your mental health, and ensure that the app is working effectively for you. It's crucial to know that you're on the right track and that the app is not worsening your mental health or causing anxiety."

"Yes it would be a good thing. Sessions always start with 'how have you been' but it never works as I don't properly recall as based on the last five minutes."

There were mixed views about making data available to healthcare professionals within the app. Some thought this would be very helpful, or even essential for some functions, and would provide for a vital human element. Others felt it risked data leaking out or being used inappropriately, as with commercial exploitation. There was a sense that HCPs based in the UK, either within the NHS or in private practice, would be subject to rigorous professional oversight. If they were based in other countries, as they might well be if employed by an app developer, this would create an extra risk.

Participants also expressed concerns about the impact on users if the

evidence from the monitoring was that they were not making progress, or even going backwards; or if the app set unrealistic expectations which they could not meet. This could create anxiety and undermine people's mental health.

#### 5.4 Al and Machine Learning

There was also a general view that the use of AI (here used to cover products employing Artificial Intelligence, machine learning and large language models) would inevitably increase in the years to come, with consequences - good or bad - which were hard to predict. Some participants thought that Al had the potential to benefit mental health care and support, in part by addressing the gap between demand and capacity in mental health services. Some were uneasy about the prospect of Al being used in DMHT, or even outright hostile. They felt it would not provide the same quality of care.

"I would not want to speak to an AI chatbot. It's not going to replace a human question."

"It would be a worry for me if they are trying to replace talking therapy. Talking about your problems is one thing. But other issues – building trust, empathy – I don't see how that can be replicated with AI."

Some thought it would compound feelings of loneliness and alienation or unreality.

"I got an ad on social media for an AI therapist and it horrified me. I was trying to get help from someone else, not to sort it out through technology."

"I always feel getting out of my house is important. If I can just stay in bed talking to a robot then it defeats the purpose."

The group discussions revealed that most participants had only a very limited awareness of AI overall, let alone within DMHT. We therefore provided additional stimulus materials using AI case studies in some groups.

#### 5.5 Future

There was a widespread feeling that the use of DMHT would expand rapidly in the next two to three years. This would be driven by a combination of:

- Innovation, including the wider use of AI;
- Need, particularly for young people;
- Lack of alternatives, as pressure on mental health services continued to grow;
- Commercial opportunities, to bridge the gap between capacity and need.

Participants had mixed views about whether this was a 'good thing' or not; but those who had doubts also tended to be fatalistic that AI would happen anyway.

#### 5.6 Case Studies

We used the review in the mid-point of the fieldwork to introduce an additional element to the focus groups, in which we presented participants with three examples of media coverage of concerns relating to digital products that would illustrate some of the themes underlying the research, particularly concerning products providing forms of diagnosis and triage and those incorporating AI. We were not attempting to evaluate the products themselves and the views of participants on them should not be taken as an informed assessment, particularly as the participants did not use the products themselves, but were instead presented with summaries of the products taken from their websites and media coverage of the products.

#### **Al Support**

Participants expressed concerns about the impersonal nature of AI compared to the need for personal responses in mental health. They saw the potential value in using AI as a triage tool to direct individuals to alternative solutions or professionals, but emphasised the importance of human connection in therapy. There was some praise for the NHS in seeking to make use of the technology in this way.

They also expressed concerns about the overreliance on technology and

suggested that using AI in mental health could be counterproductive.

As in previous discussions, participants were particularly concerned about DMHT attempting to diagnose conditions. They felt this would need careful evaluation and regulation to prevent misdiagnosis when using AI tools.

#### **Self-Referral Apps**

Most participants liked the idea of using the system for self-referral, though they would like to be assured that the product's claims are verified, and some thought that while it might reduce administrative burdens, it would not substantially address the underlying issue of a lack of capacity in the mental health system.

Some had concerns about individuals in acute mental distress not having direct contact with 'someone' (which could be a healthcare professional or a lay person) for help. Some participants thought it could play a valuable role in signposting people to sources of advice and support, so long as the process itself did not discourage them from using it. In part for this reason, it should be only one avenue of support.

**Al Companions** 

Most participants had a strongly negative reaction to the idea of Al 'friends', particularly in the context of mental

health support, including "absolutely the wrong thing" and "horrendous". Some acknowledged that this was partly about personal preferences, and they did not want to be too judgemental about those who chose to use it.

"Part of me is thinking, if people get a benefit from it, then fair enough. But the other part of me is more alarm bells ringing."

"If people want to fall in love with their [AI friends], part of me thinks let them. But it's a bit creepy at the same time."

There was some recognition of the potential benefits for individuals dealing with loneliness or depression, although there might also be long-term dependency and the risk of reinforcing negative views and undermining the ability to form normal human relationships. Overall, there was a strong feeling that AI in DMHT needed to be regulated and also that there were significant risks for vulnerable people. Al might have a role to play, but it should be seen alongside real-life connections, community engagement, and working with a healthcare professional, for example on goal-setting.

# 6. Regulation

In this chapter we report on participants' expectations of what forms of regulation are, could be or should be put in place. This includes discussion on who should be responsible for the safety and effectiveness of DMHT, management of risk and safety, the scope for self-regulation and the need for testing, reporting and guidance for users.

#### 6.1 Expectations

Most participants were in favour of the regulation and quality control of mental health apps and technologies. This covered several areas: how the products were advertised; marketing practices, including how they dealt with vulnerable people; how well they performed in providing treatment and support; and data protection.

"These technological advancements require regulations that are in line with them to prevent falling behind.
Otherwise, there will be opportunities

for scams and potential financial gain from exploiting the situation. If we can establish regulations that are as stringent as those for healthcare and apply them to mental health technology, such as chat AI, these apps could be extremely useful."

"Yes, they should be regulated.
Every time I'm on [social media] I get
bombarded with adverts – yet there is
no clinical oversight. It could be a pile
of rubbish."

There was a strong view that potential users were likely to be vulnerable to being misled or exploited.

"People using apps might be vulnerable to some degree – would not want an app that tries to sell you stuff (sharing data and then targeting you with commercial products)."

Though several participants reported poor experiences with apps, this was mainly about their functionality or effectiveness. In a few cases, the problems related to the content.

One participant spoke about how the language used by an app about OCD was inappropriate: "plain wrong". This had surprised her and she felt there should have been some checks before the product could be marketed.

Many participants said that the level of regulation should relate to the risk posed by the apps, taken together with the condition they were being used to address and the vulnerability of the user.

# "Mindfulness apps would need less regulation than apps for more severe conditions."

However, a significant number of participants thought that DMHT would be subject to little or no regulation. Some thought it was not necessary and others thought it might be impractical to regulate, because the products were developed and marketed globally.

"How can you regulate an app? You'd have to go through it with every change. It's not like a medicine. It needs to keep evolving."

Almost every participant said or agreed that there would – or at least should – be tough regulation in respect of the handling of people's personal data. This covered both the protection of data from unlawful access ('hacking') and from being passed to others, notably to use in online marketing.

"If they're handling healthcare data, it should be like the NHS, with an SOP

with very clear terms and conditions and strong controls on use. And the data should be strongly encrypted on the phone."

Many participants felt very strongly about the risks of unlawful disclosures, given the deeply sensitive nature of the data that these apps could collect and hold. Other concerns linked to the mobile phone platform included:

- What would happen if the mobile phone or app software failed to update?
- Would data be protected adequately if the phone were hacked or stolen?

There was some discussion about the need for safeguarding app users, including alerting someone if users were in mental distress or suicidal. While participants thought this was a good idea, there were doubts about whether the NHS would or could act on this, given existing pressure on resources.

Overall, participants were not really thinking about DMHT from a safety point of view, without being prompted, partly because they don't see much risk in using most DMHT and that it is easy to stop using (the view that it's not like taking a tablet which you can't un-take). The exception is where a professional or real person is involved (such as an online therapist) and the assumption here is that the therapist will be professionally qualified and accountable – though if the app/therapists were based abroad, there were some doubts about the effectiveness of that regime.

#### 6.2 Responsibility

As the focus group discussions proceeded, participants tended to think more about who was responsible for oversight of DMHT, and this led to some concerns.

"If something goes wrong, who is going to be responsible? That's what is worrying me."

## "Regulation needs teeth. Can they shut down an app?"

Only a small proportion of participants had a developed understanding of how healthcare regulation worked in the UK, including the safety and effectiveness of medicines and medical devices. There was some awareness of MHRA and NICE, though very little about their specific roles or activities. Generally people talked about 'the NHS' to refer to the whole healthcare system, including regulation. However, when the two bodies were discussed, there was a strong view that their roles should be publicised much more effectively particularly MHRA and the Yellow Card scheme. This might also apply to any enhanced guidance on DMHT, which would want to explain the roles of MHRA and NICE alongside the 'NHS' endorsement that most participants favoured. Most participants thought that the NHS website would be the best 'home' for that guidance.

Some participants thought that developers of DMHT should take

responsibility for their products, but few thought that they would actually do so. There was a view that the better or more professional developers would welcome feedback because it would give them the insight needed to improve their products, but that there would always be apps where the developers did not have the scale, capacity or interest in this.

## "I don't think the developers would do anything."

Similarly, most participants thought that the app stores did share some responsibility; and should provide some protection (such as age controls) and guidance (such as links to the Yellow Card scheme from the app download page so that it would be easier to raise concerns). But most felt that, realistically, the app stores would not do more than they were required to either by regulators or by public opinion.

#### 6.4 Effectiveness

When discussing DMHT which they had used or heard about, most participants did not think that there was a great need for regulation of their effectiveness, in part because they thought that each potential user's circumstances were unique and that products might work well for some people but not others. They did, however, feel that manufacturers and retailers would always tend to overclaim, and that where they made claims about their products, they should be required to justify these.

Some participants felt there ought to be proper evidence of effectiveness for DMHT products, although they also tended to acknowledge this might be hard to achieve. Some drew a comparison with the role of the Advertising Standards Authority in allowing such claims to be challenged, but there was some doubt as to how effective the ASA would be in covering DMHT on app stores hosted outside the UK.

"It would be great to have the evidence of what it does and trials to show the benefits. Like the way they research medicines."

"You'd want to have proof it worked, like a medicine. But how could the NHS check the data on private apps? It's a question of information and data sharing."

More positively, participants discussed the need for continued collaboration between app developers, healthcare professionals, and individuals with lived experience of mental health conditions. This should ensure that products were more effective in supporting users or patients and so lead to better outcomes for all. Ideally, the better products would become the ones presented higher up on app store rankings, and so used more frequently, creating a positive feedback loop.

Some participants emphasised the importance of ongoing research and evaluation to determine the effectiveness

of different digital tools. This needed to show a positive effect, not just absence of harm.

"It should have been tested on people who have the condition and it should show what the success rate is – like clinical trials."

Some thought that developers and apps stores wouldn't have the skills and knowledge and wouldn't be interested in testing apps to make sure they worked properly. Maybe the NHS or government could provide them with evidence on what works – including good design and user experience.

There was some scepticism towards scientific evidence, with concerns about biased results and the potential to manipulate statistics. Some emphasised the importance of scientific research and validation to ensure credibility and considerate use of these apps. Others argued that if an app works for an individual and provides positive results, scientific validation may not be necessary.

#### 6.5 Safety

In general, participants did not initially see DMHT as posing safety risks, beyond those relating to personal data and diagnosis. They had fairly low expectations as to the quality, performance and reliability of these products, but tended to the view that if the app did not work as expected, they

would simply uninstall it and 'chalk it up to experience'. Participants did not think that they were at risk of suffering harm, beyond the waste of time and money.

Some participants did identify potential risks. For example, where Cognitive Behaviour Therapy was encouraging users to uncover and dispute their thoughts, this could lead to a user developing an unhealthy relationship with their mind. Similarly, meditation might lead to 'over-rumination' in those suffering from schizophrenia. Yet both CBT and meditation were two of the most widely-used applications of DMHT and were generally seen by participants as beneficial for all and having little or no risk.

In general, even where they saw risks, participants did not favour banning products or restricting access: they preferred having much better guidance and also the use of warnings where appropriate. The one exception might be DMHT products which should never be used without the supervision of a mental health professional, such as EMDR to process trauma.

Participants did tend to see diagnosis as an area of heightened risk, and some thought that apps should not be allowed to offer to diagnose users, as this is a role for a properly qualified healthcare professional. Some also thought that, unless there were a process of regular revision, that DMHT products could become outdated and not take proper account of new insight or techniques in the mental health field: in comparison,

a mental health professional would be expected to keep up with these developments, including through formal CPD.

One significant exception was where products used AI: these were seen by some as troubling or 'creepy', and while participants could not always express why they felt this, it pointed to an instinctive sense that these kinds of products were more risky.

As discussed in Chapter 1, this view of risk and safety appeared to be influenced by the fact that most participants had not used DMHT much, if at all, and had tended to use ones which were less ambitious in the level of intervention or support they offered.

#### 6.6 Self-Regulation

There was little confidence in selfregulation and some cynicism about industry-led kite-mark schemes and voluntary codes of practice. This linked back to the perception that firms were focused on profits, not patients.

"I kept getting offered discounts from [app]. It felt very salesy, put me off. At the end of the day, they are there to make money."

Although not covered in the research, it would be an option to explore further how potential users feel about industry schemes that have achieved a measure of public awareness and confidence,

such as GasSafe for boilers or ATOL for package holidays, and whether there are features or safeguards which would be applicable in any future scheme involving DMHT developers.

#### 6.7 Reporting

We asked participants whether, if they had a bad experience with a DMHT product, they would consider reporting this to either NICE or MHRA. In those groups which were not shown the additional stimulus material on risk, very few participants thought they would do so, even if they knew how. Very few participants were aware of the Yellow Card scheme for reporting adverse effects. In discussion, some thought that they might report concerns to a HCP, particularly if the product had been provided or recommended by them. There was general agreement that it would be very helpful if the app itself could be used to raise a concern with the regulator, or at least should have information in it on how to raise a concern, much like the information on the Yellow Card scheme in the patient information leaflet.

Overall, the most common response was that they would simply stop using the app. They might inform the person who had recommended it, or leave a bad review, but almost no-one thought they would do anything else, including reporting it to a regulator.

#### 6.8 Guidance

In general, participants were (unsurprisingly) in favour of there being some kind of official guidance on the use of DMHT; sometimes this was more because there 'ought' to be guidance, rather than because they themselves would necessarily use it. (In a similar way, patients might think it right that medicines should come with a patient information leaflet, without ever reading one themselves.)

They thought the guidance might include an explanation of what different apps could do, or not do (for example, offer a reliable diagnosis), for different conditions and circumstances. It would signpost users to alternative support or indicate when they might need to escalate to a healthcare professional. Some thought guidance ought to be included in, or linked to by, the app stores or the apps themselves.

Guidance also needed to cover the regulatory process, including any scheme for endorsement or kite-marking.

"I think that the apps we mentioned, like the ones recommended by the NHS, most of them have already been approved. However, we didn't know about it. So there seems to be a problem in communicating this approval to the users. It should be regulated by organisations like the MHRA, NICE, or NHS England. But it hasn't been effectively communicated."

Some participants suggested that guidance should be extended to healthcare professionals, as there appeared to be low awareness of apps amongst these groups as well.

# 7. Young People

In this chapter we present and analyse the findings from the focus groups and depth interviews held with children and young people. This covers awareness and attitudes towards mental health.

#### 7.1 Mental Heath

Participants had a mix of negative and positive associations. The negatives included: depression, mood, anxiety (for example, when meeting new people), ADHD, bullying, sadness, feeling unwanted, paranoia, withdrawal ('keep yourself to yourself'), and being scared of what other people think (both about them as people and also about those with mental health challenges).

"Gives you problems in life and more problems later on."

"Depression, you feel left out and noone listens to you."

The positives focused on mental wellbeing and what this would allow

participants to do, such as listening to music, meeting friends, or playing football. Interestingly, young people were more likely to offer neutral views of mental health, suggesting a greater capacity or experience in thinking about the subject than older participants. These included mental health as 'what is going on in your head', self image, self worth, mental wellbeing, handling emotions, and emotional wellbeing.

Participants emphasised how much mental health education and support was available within schools, both through formal classes (such as PSHE lessons), ad hoc activities (such as a mental health awareness week), regular sessions (a 'Wellbeing Wednesday' or drop-in nurses), and access to pastoral care. Some schools even sold diaries for students to use for journaling. Most participants also mentioned school websites that encouraged students to disclose (anonymously or not) any mental health or wellbeing concerns. Interestingly, some said they would not talk to some teachers as "some teachers don't get them" and others would avoid

talking to any teacher or pastoral staff at school because they were worried they might inform their parents.

"My school is big on mental health. I think we talk about it every week."

"It's easier because they're implementing it more in schools now, making it easier for kids to actually know if something's wrong. Before, mental health wasn't taken as seriously."

"School brings people in to talk to us about it. Also on [social media platforms] is probably where we'd learn the most about it because we'll get people's actual opinions who've gone through stuff."

Yet despite the best efforts of many schools, mental health was still the subject of stigma.

"Even talking about your feelings, some people will call you horrible names. [...]. People are afraid of being judged. In school they're trying to make it easier, it just depends on the individual at the end of the day and the perspectives of different children and who they're actually with on a day-to-day basis."

For some, social media also plays a role, either through sharing stories between each other or hearing from celebrities. Others are more critical: good at raising awareness, but also fuelling misdiagnosis and causing harm. Specific apps were

also mentioned frequently, though not always approvingly.

"[social media platform] educates me on everything – shows what it's like but nothing about what helps."

"I think the internet is a mixed place when it comes to mental health because there are lots of useful resources but some websites might be a bad influence."

While most young people thought it was now relatively easy to talk about mental health, because it is promoted in school and more accepted in society, they recognised differences by type of condition. For example, ADHD is seen as easy to talk about, but depression or bipolar are harder to do so as these are seen as "bad mental health conditions". Also, casual discussion amongst young people or on social media could be misleading as well as illuminating.

"Depression is more of a severe thing and people use it really loosely for being sad. Spread on [social media platform]is giving people a different representation of what it is like."

Further, they recognise that mental health is personal and individuals will feel different in how comfortable they are to talk about it. Positive peer support and friendship networks can play a crucial role here.

"Friends play a big role and just being with them is important."

"Might be hard to tell anyone. It can be hard to open-up even to friends."

"You can talk to friends as you trust them the most to keep it to themselves."

Some participants felt that mental health could be "over-discussed" and this encourages some people to self-diagnose with conditions to "one-up" their friends.

Some mentioned the support they get from their parents or family, but this was not consistently given and the general feedback was that this can vary considerably from family to family and an individual's relationship with their parent or parents. Sometimes talking to any adult, whether art school or home, was difficult.

"My parents are very traditional and don't like talking about it, but I can at school."

"It's hard for young people to talk to an adult. Adults may not get what they are saying or relate with them or the issues they're going through."

#### 7.2 Attitudes towards DMHT

Participants were broadly positive about the use of DMHT. One of the most common themes was that anonymity helped them to express themselves and feel they would not be judged. "Apps are a convenient way to help themselves without being judged by anyone else."

"These tools can be helpful for individuals who prefer not to talk about their mental health with others."

Sometimes DMHT was seen as a remedy to problems of access or the lack of effective alternatives.

"It's a long journey to get professional help. You can experiment yourself with what tech helps and it might work for you and so you'd not need professional help. If they don't work then you still can get mental health support. It can help you understand your struggles and also be able to talk to people who go through the same things."

"It's a good idea because it's easier to access and more people can get help instead of having to wait for counselling and some people may find it easier to write how they are feeling rather than struggling to find the words or sentences."

Apps were also seen as providing support for maintaining good mental health as well as when things were not going well.

"It can be helpful to provide resources as some people might not know where to go to improve their mental health."

A few participants thought that DMHT

might prove more effective than 'traditional' approaches, or preferable, particularly for those who have grown up with digital technology.

"I've been seeing a professional for ages and it's not helped at all; but some self-help techniques I've found have helped."

"Nowadays everyone my age does everything on apps, it's all about technology these days, social media, and apps. It's much more preferable for us that everything is done digitally. We've been going to school and learning through Teams. Technology is getting more advanced and we just prefer it."

A more common theme was that everyone's mental health experiences were different, and so the wider the range of support on offer, the better.

"People react differently to different things – might feel more comfortable talking to or using tech. Different coping mechanisms. Everyone has their own opinion on what works for them."

As with older participants, there was caution about DMHT becoming the only route to access mental health support.

"It should not be the only option.
But it's a good option if you can't get
professional help because of demand
or money."

"If you are really struggling, apps can

help, but they're not going to cure you so you might need to go to a professional in real life."

TikTok was one of the most commonly-used digital resources for mental health. Participants had mixed views about it. Some were sceptical of it, saying it could make mental health worse through misinformation. Also, quizzes and fake assessments were a problem. But others said it had useful information and motivational quotes, and also had positive views about the role of influencers in spreading information and advice about mental health. They also frequently expressed confidence that they were 'savvy' enough to avoid these risks themselves.

#### 7.3 Features

We asked participants their views about a range of potential features that DMHT could provide.

Anonymity. This was one of the features of DMHT as a whole which young people mentioned the most often. They valued the opportunity to speak anonymously, in part because it avoided embarrassment or feeling judged, in part because it allowed them to remain in control of the process, compared to speaking to, for example, a teacher who then might feel obliged to inform their parents. The strength of feeling was such that even having to provide basic information such as their email address or date of birth might discourage a prospective user.

"I think it's quite good because you know it's anonymous and you can stop it whenever you want. I think that people can be more open because they know that the person they're talking to doesn't know who they are, and they can't tell other people like their parents and stuff."

Guided exercises. Participants were positive, seeing such exercises as helpful; but they thought that many users would lack the motivation to make use of them. Also, there were already a lot of apps with this feature.

"For me, it's not number one as I feel it is widely available already and I could go to [video content website] and get really high quality resources for this already."

**Family context.** Some young people thought that DMHT would help those whose parents either did not understand the challenges of mental health, or actively denied there was a problem.

"Some parents don't believe that mental health is a thing, they think it doesn't matter, or it's just hormones or something, so if people are really struggling and their parents don't believe them, then these apps came be a great way for them to actually get help."

**Information about your condition.** This was generally seen positively, as it would allow people to find out why they were feeling as they did or what was worrying them. For example, if you typed 'what to do when feeling sad' into TikTok it would

come up with lots of videos, and these were often very accessible and also made by people who were relatable. Participants also thought information might help if the user was confused about their state of mind, but they also worried about misdiagnosis and about false information. Some thought it might be better to use it to gain more information once they had a diagnosis from a healthcare professional.

Peer support networks. They were in general very positive about being able to talk to others with similar conditions or experiences. It would help people feel less isolated and allow them to explore their experiences with others, and offer help and mutual support.

"You can feel very alone so it can make you feel a lot better."

"[Social media platform] is kind of like that, seeing people post things that you relate to, you know that you're not alone."

"It can help you at a deeper level and a professional might not really be able to understand what you're going through."

There were some concerns, including whether forums could become 'competitive', or might 'fake' symptoms to gain more sympathy. One factor was the extent to which forums would be moderated or supervised, but even here young people were much more positive than older participants.

"It could become an echo chamber, but could be good if regulated or if a professional present."

Remote contact with a mental health professional. Again, this was received very positively, even where the contact was through a digital channel such as a text or messaging. The key was how responsive or 'available' this contact would be, and in this sense the feature was seen as compensating for the perception that traditional mental health support was very hard to access and also provided in an inflexible form.

"Definitely better than talking to a bot."

"You can talk to them sooner, so if you're having a panic attack compared with traditional therapy, say once a week, where you have to wait."

Another strong perceived advantage was that some users would be more comfortable interacting with a mental health professional via an app than face-to-face. It might also provide more anonymity.

**Simulated experiences.** These would be scenarios or other exercises to help people to explore sources of anxiety or other conditions in a safe environment.

"I guess with that it would probably work for some people and not for others. I would definitely be willing to try it - if I was anxious about something." Participants thought this might not work for everyone: some would give it a go, others wondered how safe this would be if the apps were not monitored by a HCP.

**Stop-gap.** As with adults, young people recognised there were constraints of resources, though they tended to express this differently. Some also expressed strong frustrations with the local Children and Adolescent Mental Health Service (CAMHS). DMHT was therefore seen positively as a stop-gap, while waiting for access to other support.

"People who help with mental health can be quite busy so they might not have time to actually help you in real life. So while you're waiting the app can keep you going until they can see you properly."

#### 7.4 Using DMHT

We asked young people about their experiences in using DMHT. As with the discussion in Chapter 4, this was not intended to provide an assessment of specific products and the examples are used to illustrate different perspectives towards DMHT as a whole.

The most common uses for apps (including those in the wider definition of DMHT) was to support people's 'mood', particularly for stress and anxiety. The tools included meditation, managing symptoms such as breathing routines, expression (which could range from simply writing down how the user felt

when they wanted to through to more structured journaling) and motivational messaging (such as apps that provided an inspiring quote of the day). It was striking that participants often used these for a relatively short period, for example to cope with additional stress during exams.

# "[Social media platform] has a function where you can write your feelings and then "burn them" – it helps you to get out bad feelings and let them go."

The main concern that participants expressed was with self-diagnosis, particularly where this was done in a casual way, such as "Five ways to tell if you have autism or ADHD". These kinds of simple tools or quizzes were seen as too generic to rely on, and also risked trivialising or normalising conditions.

Sometimes, users' experiences were linked to their expectations, For example, Kooth was recommended by schools and offered the chance to speak to a professional if someone needed to urgently, as well as a weekly timetabled session and the chance to read about the experiences of others.

## "You can go on where you can talk to people in real time which is really cool."

Users also liked the way it was anonymous, but you could identify yourself if you chose to, and that you could add notes. But users also expressed frustrations, including that it could take hours or even days to get a response. There were also features such as using a chat function to engage with a healthcare professional, which some liked and others didn't, saying it "didn't feel like talking to a human".

#### "I don't like it as it stops at 10pm and after ten is when you need it. It's at night when you have dark thoughts."

Part of the context for young people's views of DMHT was their experience with Childrens and Adolescent Mental Health Services (CAMHS) in their area, which were often influenced by problems of access and waiting times, both to be referred to CAMHS in the first place and in receiving specific help such as a phone call with a counsellor. We did not attempt to make an overall assessment of the service provided by individual CAMHS in different areas. or to elicit positive experiences that participants might have had but chose not to mention. What we can say is that a majority of participants perceived CAMHS as having a bad reputation and unable to provide much advice and support.

We also showed participants two examples of DMHT apps. The first demonstrated the wide range of tools and support an app could provide. Most participants thought this could "really help" someone as you could talk to a human but you didn't need to: you could just use it as a place to express yourself and to try and work things out. The range of tools and options was particularly appreciated.

"It's a good starting point. It does seem a bit too bot-like and repeats the same phrases and has no relation to what it's saying. You can then move on to human therapists."

"It's good if they [a potential user] don't have anyone who they think can help them or understand what they are going through."

The second example illustrated the use of AI in DMHT. Participants expressed some concerns – more about the use of AI in principle rather than the product itself. They thought that AI could not provide emotional support and could not read another person's emotions effectively. They felt it could teach a child to hold some of their feelings in and encourage them to talk to the app and not to talk to someone in real life. They noted it was "clinically validated" but this did not override their doubts about the effectiveness and appropriateness of AI.

"What if it gives the wrong advice? Like the [AI bot] – it can tell you some weird things."

"If the app gave misinformation that could be quite harmful."

#### 7.5 DMHT in Wider Healthcare

We explored how young people thought DMHT would or should be integrated into the wider healthcare system.

This covered how they might receive

information or recommendations about DMHT; the need for parental consent; and views on monitoring their condition through apps.

One distinctive issue for young people was that they were frequently not allowed to use their phones in school, even during breaks, so they would not be able to access DMHT a lot of the time. Some felt allowing them to use phones and therefore DMHT would be beneficial, for example if they were stressed or were anxious about an upcoming lesson.

#### Information and Recommendations

As with adult participants, young people had a range of potential sources of information and advice on DMHT and were likely to use a mix of sources, with trust and understanding the two critical factors. This included reviews and star ratings (where young people were more likely than adults to say they would rely on these, perhaps because they were more confident about being able to tell genuine from fake reviews), or information coming from a familiar website. They also looked for a guarantee that the site or app would not collect personal data, and also felt that if the app charged a fee, it would probably be a better product.

They tended to say that trained therapists would have the best knowledge and have a toolkit of the sites or apps that would be most useful and appropriate for each individual. Friends

might recommend an app, but might not understand your condition properly.

"I'd trust my friends and teachers mainly, people I already know. Someone else, I feel like they would just be looking for a sale. I wouldn't trust social media; an influencer, it would have to be a really specific recommendation."

"I would probably trust my best friend or maybe a teacher who I trust if I'm having a hard time with something. Or an influencer that I know is dealing with something similar to me."

There were mixed views about the role of celebrities and influencers. The former were useful for raising awareness, while influencers were often seen positively if they combined trust with a shared understanding of the condition. This was distinct from influencers who were merely promoting the product for a fee. Some young people also thought that the more popular an influencer, (for example, having over a million followers) the more credible they would become.

"Influencers probably yes, because they're really popular and if they were to recommend an app it's probably for a reason – because they're really influencing a lot of people and they wouldn't be recommending a site or app that isn't good."

"I don't really trust them because they get paid to promote stuff so you don't know if they're promoting it because they actually like it, or because they're being paid to say so."

Participants thought that if a product was recommended by a school, they would expect it to be effective and safe to use.

### Involvement of Healthcare Professionals

A majority of participants thought that they should be free to use DMHT without the direct involvement of HCPs. This was in part because they saw DMHT as being used in different ways, some of which were non-intensive or exploratory. It would also gain the most benefit from the flexibility and accessibility of DMHT. Some did say that, while it should essentially be the individual's decision, there would be times when an HCP would need to be involved.

#### **Parental Consent**

Young people felt strongly that parental consent should not be a requirement to use apps, because this might deny them access to the support they needed and was an intrusion on their privacy. Even when some accepted that an age limit might be appropriate, they felt 18 would be too old, as people struggle with their mental health before then.

"If you're over the age of thirteen you pretty much have unrestricted internet access anyway. You shouldn't have to ask permission to use something that can benefit you."

"Some people might not be able to reach out to their parents so an app might be able to help them without their parents knowing."

#### Monitoring

There were mixed views on whether young people's use of apps should be monitored by a healthcare professional. Some saw this as invasive, and might lead some users to restrict how open they were with the app, so in part defeating the point of using DMHT

"Depending on the situation, I would feel maybe uncomfortable because it is personal to you and not really their business."

"Privacy is important, and individuals should have the choice of whether to share app usage with healthcare professionals."

"It's like someone inspecting your brain."

Others thought it was more positive and supportive, particularly where it could track progress or where it meant that 'someone with feelings' would be part of the process. Several thought it would depend on the relationship they had with the healthcare professional, and that the arrangement should be transparent.

"Maybe not monitor everything, but certain things could be flagged up – like if someone mentioned they were feeling suicidal." "If someone is going through something quite severe, then if there's someone monitoring, maybe they could reach out to make sure it doesn't go any further, or can threaten that person's life."

"It makes it feel more professional, more helpful. It's not just software monitoring you, you'd have an actual person with professional opinions. Privacy could be a negative, some people are paranoid about that."

#### Guidance

Young people wanted any guidance to highlight that DMHT might not work for everyone, or every condition. Users should be encouraged to still seek professional help if they felt they needed it, and DMHT itself (or the app stores) should signpost how to get this help. This information should be clearly set out, not hidden away in Terms and Conditions (particularly as no-one reads these.)

#### 7.6 Regulation

Participants expressed a strong desire for having a trustworthy website or app to use. They would look for information on the app store, including awards or star ratings, and the number and quality of the reviews, placing additional reliance on evidence of how other people had been helped, and on more recent reviews. Some also said they would assume the most frequently downloaded

apps would be the most secure.

As with adults, children and young people had little idea about the regulation of DMHT, and they tended to think that there was little or no regulation in place.

"I would imagine there is an agency of some kind assessing it."

"Would hope it was regulated but wouldn't expect it to be. I don't feel developers have that kind of insight."

"Feels like it's not exactly checked. I feel it needs an incident to happen to cause something to happen."

Their main concern was privacy and data security.

"At the end of the day a company needs to make money – so it needs to be heavily regulated not to sell data to [a retailer] who then promotes stress toys to you. The data they have has to be held securely."

There were a few examples of other features that would need to be regulated, such as controlling the use of 'triggering' words.

"Regulation is needed – like a system that can block certain words like on [social media platform]."

Some thought that the very wide range of DMHT meant that it was more important to make sure young people

understood the risks of DMHT and could make informed judgements, rather than trying to regulate every single product. Also participants were more likely to say that the app developer is responsible for ensuring the quality and effectiveness of their apps, though few suggested how this could be done.

"Some apps ask for feedback from users, so maybe they use this feedback."

There was general agreement that the purpose of the DMHT product or technology should determine if a product needed to be regulated and, if so, to what level.

"It depends on the purpose of the app – if it's talking to someone, you need to check to make sure it's not damaging. If a tracker then less so – doesn't need to be that regulated. It's a stopwatch in a kind of way. You're not being steered into the wrong direction."

The same applied if the app made use of humans to monitor use or provide advice and support.

"Do background checks on volunteers or people providing advice."

We asked what participants would do if they had a bad experience with DMHT or thought it might be doing them harm. The majority said they would delete the app and probably find an alternative, but not do anything else. Some said they would leave a bad review on the app store, or might report it to whoever had recommended it to them, such as a school. As with adults, young people found it hard to see DMHT as inherently risky, although they did mention trigger words and misleading or malicious advice on forums as potential risks.

This changed when young people considered AI, where they felt a much higher level of regulation was needed compared to 'basic' DMHT. In large part this was because many young people shared the same sense of doubt about how effective AI really could be, and unease about its artificiality and lack of true empathy.

"I think it would be quite creepy, because it's not a real person. When you talk to a real person they have human feelings and they can empathise with you; but AI is just talking to a robot and I don't think it could give you the same help as talking to a real person."

#### 7.7 Summary

The young people we spoke to said that DMHT had a positive role to play, but that it was most relevant in treating symptoms such as anxiety, stress, OCD by providing support or distraction, rather than tackling the underlying causes. DMHT – including Al – was not a replacement for in-person, professional help if that was what was needed.

Overall, the main perceived benefits of DMHT were that it was:

- Easy to access.
- Provided a safe space without judgement, particularly when anonymous and/or more private.
- Familiar to young people, who are used to using tech.
- Less embarrassing.
- Avoided needing to talk to an adult (or any 'real' person).
- An alternative if there was no-one else to talk to or people (particularly parents) did not feel comfortable talking about mental health.
- A chance to "get it out there", even if it couldn't solve the problem.

The main perceived risks or drawbacks were:

- It might reinforce negative feelings.
- It might sell or even steal personal data (particularly through fake websites).
- It could provide a space where people share suicidal thoughts.
- It could divert people with serious conditions such as schizophrenia from getting professional help.

Above all, participants wanted choice and a mix of support, as some prefer talking to someone they trust, while others prefer the anonymity of an app; and both might be important at different stages of someone's mental health journey.

"Mental health is very personal. The same symptoms can mean very different things to people. Tech is not sophisticated enough to tailor to everyone."

The fieldwork with young people included one-to-one interviews and these provided additional insight into the 'user experience' as a whole as well as in relation to specific issues. Some examples of these individual perspectives have been included in Annex A.

## 8. Other Differences

The relatively large number of participants allowed us to explore differences in people's views and experience by a range of demographic and other factors, including by condition; community and culture; income and deprivation; class and educational attainment; age; and location (England, Wales, Scotland and Northern Ireland). In this section we explore some areas where we are reasonably confident that the evidence reveals meaningful differences.

#### 8.1 Conditions

When discussing attitudes towards mental health, many participants made a distinction between conditions which are relatively familiar to the general public and those which are not. For example, depression and anxiety were experienced by everyone to some degree, and so were more familiar and easier to engage with. In contrast, conditions such as schizophrenia were seen as 'different' and therefore attracted more stigma.

This had implications for how people might think about DMHT, particularly because it can be more discreet both for exploring a potential (self)-diagnosis and for receiving support via an app rather than medication or face-to-face sessions: and this might mean that apps either aimed at or used by people who had or might have conditions with a higher level of stigma might also have a higher risk profile.

There may also be an issue for how apps are designed and marketed. Manufacturers may not want to refer to conditions with higher levels of stigma in their product descriptions or other marketing, because this might discourage others from choosing them, and this would potentially make it harder for users to identify suitable products.

#### 8.2 Community and Culture

Most participants from an ethnic minority said that there was some level of heightened stigma around mental health in their communities. This prevented people from talking about it, or seeking help and support. This perspective was often strongest when people had moved from another country to the UK or where they remained close to their country of heritage.

"I come from a strict Caribbean background and we are behind other communities."

"In my community [Pakistani heritage], if you say you suffer from depression, they say 'sort yourself out'. There's still not a lot of help or understanding."

"In Nigeria people don't believe in mental health. They think you are possessed by evil spirits. When I moved to the UK, it's different. In Nigeria, you're told to stay away from people with mental health issues and families will hide their children with disorders."

These perceptions had the potential to make DMHT more attractive to members of communities where attitudes were less supportive, because it was more discreet. It would also make the availability of effective guidance more important, as potential users of DMHT might be less likely to turn to family and friends for advice.

#### 8.3 Income and Deprivation

Several participants in the focus groups raised concerns about access to technology and in particular to smartphones becoming a barrier to accessing mental health support. The more that DMHT was integrated into care and support, the harder it would be for those who did not have the right technology. (This would not only apply to having any kind of smartphone, but also to products that required the latest phones, for example by not operating on older operating systems.) This was also raised by several of the intermediaries.

"I've worked with people in smaller housing projects, particularly younger individuals who couldn't afford smartphones. In cases like these, where individuals are reliant on Universal Credit, smartphones are not an option. Nonetheless, these individuals still require mental health help."

There may be parallels here with attitudes towards other forms of digital transition, and resulting questions of access. It also connects to the strong concern expressed that DMHT would not be appropriate for many potential users on health or welfare grounds, and that DMHT needed to be deployed within healthcare in ways that allowed people to opt out without suffering any loss in access or care quality.

#### Class and Educational Attainment

There were some views expressed about the implications of class and educational attainment for the effective use of DMHT. It could be more 'democratic', because it would benefit

some people who might be intimidated by healthcare professionals. But for those who were not confident about advocating for themselves or for family members, it could mean they might be given a DMHT 'solution' that was not appropriate to them, while more educated and confident patients would press for and be given alternatives.

In our experience, class is a major factor in people's experience in accessing healthcare but this theme tends to need a lot of time and space within focus groups to emerge. (As with other forms of discrimination, participants often need to hear from others before they feel confident about expressing their feelings that their experiences are linked not to them as individuals but to bias within society.) Given that the groups in this project were covering a lot of ground, it may be that this issue would emerge more strongly in research aimed more directly at this issue.

#### **Older People**

Participants felt that the wider use of DMHT in healthcare raised concerns about the position of older people. The two main issues were about access to alternatives and vulnerability. The first related to the wider issue of whether those who could not or would not use DMHT would become disadvantaged. The second was whether encouraging older people to use DMHT would open them up to being mis-sold DMHT products, or being overcharged (for example, if they were not aware of the

concept of in-app purchases). Some developers might even target this group with 'predatory' apps with unfair terms and conditions.

Participants were recruited using an online methodology and so we did not hear directly from those who are digitally excluded: in effect, participants were 'advocating' in the research for family members or friends who they could imagine being disadvantaged by DMHT. But the desk research identified the potential of DMHT in addressing issues such as isolation, access and the impact of ageing on mental capacity which are of particular relevance to older people; but less research on the barriers to DMHT uptake or effective design for older people.

#### Male and Female

Participants frequently referenced traditional male and female gender models, and in particular the view that women were 'better at communicating' or 'sharing their feelings' while men were more reticent or reserved. More often participants talked about these models being challenged or being less rigid, with men more able to open up; but some still saw these models as being real barriers to people (almost always men) recognising their symptoms and reaching out for help.

## "Boys don't cry. Men don't get depressed."

Some participants suggested that men

might find DMHT helpful because it would allow them to feel in control of the process of exploring their condition and considering potential routes for treatment and support, compared to a face-to-face approach to a healthcare professional. Some suggested that aspects of DMHT, such as connecting to others facing similar challenges, might suit women better. Some female participants reported that they had experienced having their mental health symptoms downplayed by healthcare professionals; or feeling reluctant to discuss challenges they were facing, particularly as a mother. Here, DMHT might provide an alternative. There was also some discussion about the wider differences in male and female experience of healthcare (for example, the higher prevalence of depression amongst women, or women finding it more difficult to have their symptoms or conditions accepted by healthcare professionals).

"Diagnosis could be useful if you have had your condition recognised. Like with late diagnosis of autism in girls. That's really scary."

The enduring role of gender may have implications for the design of DMHT, and potentially for how they are recommended to potential users. No participant suggested there should be 'male' and 'female' DMHT: but they did stress that people should have a choice about DMHT products, and that they had tended themselves to try out a range of apps to find out which one

suited them best. It may be that having multiple apps would allow users for whom gender models were an issue to find one that was appropriate for them.

#### Scotland, Wales and Northern Ireland

We ran groups with participants from Scotland, Wales and Northern Ireland to explore how differences in the healthcare systems might lead to different expectations or preferences, and to reveal other differences in each nation. For the most part, those differences were not significant. One exception was some negative perceptions of the UK-wide regulatory regime stemming from the PPE scandal: could regulators be leaned on by politicians to approve apps or promote their use?

"I'd trust a Scottish NHS endorsement, but not an NHS England one. It's too vulnerable to lobbying."

#### **Parents**

We asked parents of younger children for their views on whether children should have access to DMHT. There was some support for this, and also a lot of concern as to how this could be done. Several participants praised schools for providing good mental health support as a whole, and this included providing digital resources on the school website.

Parents thought It was important to tailor the design of the apps for children with specific needs, such as autism. There were also some doubts about costs and the use of in-app purchases. It would be crucial to have a means for monitoring children's interactions on the apps, including who they are talking to if forums were included.

But there were strong concerns about children having access to DMHT too early in their lives, and also to more potent apps. This was seen as part of a wider problem of access to digital technology, where parents were fighting a battle against peer pressure.

"The regulation for apps for kids is nowhere near where it should be. Kids access far too much content they shouldn't. I would not feel comfortable with kids accessing without more safeguards."

While parents expressed concerns, they also tended to see it as inevitable that DMHT would play a role in their children's lives, because of the wider centrality of mobile phones and digital products. They also felt the experience of growing up in a digital world would make children more streetwise: although, for example, several parents were concerned about the potential for platforms such as Tik-Tok to spread misinformation, they also thought that most young people were well-placed spot misinformation.

## 9. Intermediaries

In this section we review the views of intermediaries who acted as points of advice or guidance for those whose role included supporting children and young people's mental; health and so who had valuable perspectives on the role of DMHT.

We spoke to ten adult professionals who worked with children and young people in different roles: five children's social workers and five educational professionals working in SEND and/ or safeguarding. These intermediaries or 'key informants' gave us additional insight into the potential role of DMHT to complement the focus groups and interviews we held with children and young people (for simplicity, 'young people' here includes children).

The discussions with intermediaries were structured around these broad questions:

- How easy or hard was it for young people to talk about mental health?
- How did they receive mental health support?

- What were the main barriers to receiving that support?
- How could DMHT contribute to mental health for young people?
- What were the problems or risks for young people in using DMHT?
- What were the views of intermediaries on regulation of DMHT?

#### 9.1 Talking about Mental Health

Intermediaries broadly agreed that it was much easier for young people to talk about mental health now compared to previous generations, in part because of coverage in the media (including social media), and in part because of the work of schools and other services. It was less 'taboo' for young people to talk about feeling anxious or being worried, and they had a better vocabulary to discuss mental health. While discussing mental health was becoming normalised, young people still needed to build up trust with an adult before talking to them frankly.

#### 9.2 Receiving Support

Intermediaries reported that young people received mental health support through a range of channels: the most significant by some way were schools, but there were also drop-in groups, lunchtime sessions and counsellors, some of which might be arranged by schools, others by the community. Young people made use of social media and helplines. There were also the local Childrens and Adolescent Mental Health Services (CAMHS) providing more formal care and support.

#### 9.3 Barriers to Support

The main barrier was the prevalence of very long waiting times for all stages of the journey to support and treatment: access to a GP; referral for assessment; and then referral for treatment through CAMHS. Post-pandemic, intermediaries reported waiting times of two to three years for a referral. This lack of capacity within the NHS (and to some extent within schools and local authority children's services) had also led to overreliance on the charity sector.

Other barriers cited included:

- Digital exclusion, where children did not have access to the technology increasingly relied upon to access services and provide support.
- A lack of understanding or support from parents and families.

- Parents lacking the knowledge or confidence to ask for help or support for their child, sometimes for fear of the potential perceived consequences; and also lacking the knowledge of how to access services.
- Religious or cultural barriers.
- A lack of language of means of expression for (particularly primary age) children to express their needs or problems.

#### 9.4 How DMHT Could Help

Intermediaries saw DMHT as able to reach more people, with a greater degree of flexibility. Sometimes it would be easier for a young person to 'talk' to AI than to a real person, and it would also help those who were 'non-verbal' (and would have the scope to be developed specifically to serve this group).

They thought it might be particularly valuable in the early stages of a developing mental health challenge (which might link back to the problems posed by the very long waiting times for other forms of support) and where symptoms were relatively low-level. This includes the early stages of anxiety, depression and stress - for example, during the separation of the child's parents or during exams. Beyond this, intermediaries mentioned a range of conditions where they thought DMHT could help, including ADD, ADHD, anxiety, ASD, depression, eating disorders and 'low moods'.

### 9.5 Problems and Risks

For intermediaries, the main concerns were linked to safeguarding: above all, ensuring that peer chats and forums were properly monitored. Using DMHT might also trigger traumas because there were not healthcare professionals present to ensure the process was appropriate to the individual; and also if young people were retraumatised, there would not be HCPs there to provide support. Again, this might be a particular risk with forums.

They were also concerned about diagnosis and self-diagnosis and the risk of people being affected because of 'labels.'

# "Labels stick, you can't un-diagnose someone."

Other concerns raised included:

- How DMHT could tailor support to individuals (for example, those who were neurodivergent, or had attention disorders.
- Acute mental health conditions which would require clinical support of a kind DMHT could not provide.

Whether extending the use of DMHT would lead young people to feel of less worth, for example thinking that HCPs did not have the time to talk to them.

# 9.6 Regulation of DMHT

There was low awareness of what is done and by whom. In terms of the level of regulation, there was broad consensus that this should vary depending on the purpose of the app. If it were something basic, like sleep hygiene, it would not need to be highly regulated. In contrast, an on-line counselling service would need much greater supervision. Intermediaries also stressed the need for stronger regulation, depending on the type of personal information being shared by the user. There were several other comments on what regulation should ensure:

- That trained professionals were involved where apps were seeking to provide care.
- There should be appropriate pathways and interventions to assist users to transition to more suitable support if needed.
- There should be effective safeguarding, with escalation of care if necessary. Where there was some risk of harm, there should be follow-up mechanisms. Apps should be structured in terms of access and content to reflect the age of users, as with in-person care.

There should be a solid base of evidence on safety and efficacy for apps.

"If it's to support someone with a particular diagnosis, that it meets those needs and is based on research or a therapeutic background." Overall, the intermediaries we spoke to were open to greater use of DMHT: their main reservation was that technology could lead to people having worse mental health, and DMHT should not encourage greater use of devices or divert young people from human interactions or real-world interactions such as exercise or group activities.

# 10. Implications

In this chapter we summarise the core attitudes and priorities shared by a clear majority of participants and then reflect on the implications for guidance and communications. We also explore the scope for segmentation, behavioural modelling and further research.

#### 10.1 User Priorities

We had contributions from over two hundred people and summarising their contributions inevitably requires some bold simplifications. Despite this, three core attitudes and priorities of participants were clear.

**Integration.** DMHT should be integrated into wider mental health services, not replacing health care professionals but providing additional support or freeing HCPs up to focus on where they can help the most.

**NHS Endorsement.** There should be a process by which the NHS endorses

the best product or products in each category, supported by well-publicised guidance on best use and any risks for different people or conditions. (Some even favoured an NHS App for mental health.)

**Regulation.** This should be commensurate with risk both by type of app and the vulnerability of the user. Data security needed a very high level of regulation. Diagnosis and therapy also needed strong regulation, and to a lesser extent to monitoring – particularly so that where users of DMHT have concerning patterns, there should be an intervention by a HCP.

#### Risk and Benefit

Participants had some difficulty in engaging with the risks and benefits posed by DMHT because they had comparatively little experience of some of the categories of DMHT products and because they did not perceive them as offering much risk. This may mean that users may not report problems with DMHT because they will not recognise

any harm, or will attribute it to other causes, or even if they think the product is not helping, they will not report it in the way they might an adverse reaction to a medicine. They may also make decisions on using DMHT that are more 'risky' than if they were making a fully-informed choice.

This said, the discussions did lead to a clear sense of where risk might lie, and the ways in which DMHT users might think about and put a value on that risk, to compare to the potential benefits. We have formulated two rubrics or 'rules of thumb' to capture these.

#### The 'Care or Cure' Rubric

Participants saw DMHT as providing different levels of care, ranging from products helping to maintain wellness and forming part of their 'self-care' regime, to products playing a significant part in managing serious mental health conditions. But they distinguished 'care' from 'treatment', and the management or reduction of symptoms from treatment of the underlying causes. There was a strong feeling that DMHT could not (at least, not on its own) provide a 'cure', in the sense of tackling the underlying causes of their condition. Where DMHT was intended or being used to 'treat' a mental health condition, then it took on a much higher risk profile and should be regulated accordingly.

#### The 'Real-World' Rubric

Participants saw risk, and the way DMHT

products should be regulated, as linked closely to the 'real-world' activity the product sought to replace. In short, if an app were replacing a physical object or process – a self-help book, journal, yoga class or meditation session – concern is low. If it were replacing a human – diagnosis, triage, therapy or case management – concern is much higher.

For example, a basic mood monitoring app was in effect a digital version of a paper diary, and so did not require much if any regulation, just as printed diaries themselves are not regulated. In contrast, a diagnostic app was seeking to replicate a healthcare professional, and so needed an equivalent level of regulation and oversight.

This could also help unravel some of the issuing arising from the use of apps within wider mental health support. In this example, someone using a diary to record their moods might need to be guided on how to do this effectively, and also avoid the risk of - for example - a series of days where they failed to meet their targets leading to greater anxiety or other negative feelings. With a paper diary, this responsibility would fall to a therapist or counsellor. If the app took on this function - that is, providing support for the mood monitoring, or interpreting patterns with the data recorded - then it would be replacing a HCP and would need a much higher level of regulation or assurance.

This rubric may also help indicate the type of regulation which users

would expect. In the case of mood monitoring, a plain printed diary might be supplemented or replaced with a 'self help' book in which a healthcare professional would set out strategies for using mood monitoring, including risks and benefits and an element of coaching. The book itself would not be regulated, but the author would be governed by professional standards as well as the need to manage their reputation, and this would provide some additional reassurance to the user. So we might predict that the involvement of healthcare professionals in the development of a mood monitoring app would be a major part of how users might see them in terms of credibility and risk - and this is exactly what we heard from participants.

This may imply that professional bodies such as the Royal Colleges and professional regulators will have a significant role to play in guiding members who might be associated with developing or endorsing DMHT, so that their actual role and responsibility is clearly communicated and matches to the expectations of users. This would include those providing advice on social media channels.

### 10.2 Information and Guidance

For the most part, participants had not thought about regulation prior to the research and did not always have a clear idea about what form it should take as a whole, though they did have clear views on aspects of it – such as protection for vulnerable users. But participants were much more clear as a whole about their expectations for information and guidance. They thought this should cover:

- As a first priority, a checklist of potential risks and benefits which people could use when thinking about or choosing DMHT.
- A list or register of products which had been endorsed or met a set of standards so people could see which apps were suitable and effective for people to know what apps are medically useful.
- A list of the 'best' (most effective and safest) DMHT as recommended by the NHS or mental health charities.
- Much more publicity on the regulators (MHRA, NICE and 'the NHS', which would cover bodies responsible for professional standards amongst healthcare professionals) so people could understand their role in regulating DMHT and so have more confidence in selecting and using DMHT.
- Making sure information and guidance was designed for and reached those who might act as intermediaries or advisors, such as employers and schools.

The guidance should be available through the NHS website, and should also be diffused more widely and in different formats, such as YouTube and TikTok. It should also be linked to or

summarised within apps themselves and on the app stores.

Participants also stressed the need for guidance for those who might be involved in advising in the design or use of DMHT. They thought this was as much if not more of a priority than guidance for the public. The main groups of intermediaries were:

- Healthcare professionals, both in general practice and specialists in mental health.
- Teachers and school management.
- Employers (both line managers and human resources teams).
- Developers (covering both the need to draw on the insight of mental health professionals and on the 'user experience' – for example, balancing making DMHT engaging without creating an unhealthy dependency or anxiety).
- App stores.

These two strands of guidance should ensure that anyone being recommended DMHT or seeking it out themselves should know:

- In what circumstances and in what way the product could help them.
- When or how it could not help, and they would need a different product or alternative care and support.
- Any warning signs that might arise from its use, such as anxiety.

How to get help if the product was not providing the care and support they needed, or might be causing them harm.

# 10.3 Segmentation

The research was not designed to produce a formal segmentation of public attitudes to DMHT: this would require a representative survey with a larger sample. However, even with qualitative data we can discern some patterns within the findings which – used with caution – could help with current thinking and for planning future research.

One of the key moments in the potential use of DMHT to provide a significant level of support to a user would be where an app or similar tool is recommended to a patient by a healthcare professional. We have analysed the responses that directly address this situation, or which provide relevant context, and we have identified five potential responses.

No thanks. Users who feel DMHT is not for them because it is digital and/ or based on a mobile phone, and they think that (1) technology is the problem in mental health, not the solution or (2) that additional use of or dependency on mobile phones is a concern or (3) that the DMHT approach would be of lower quality or higher risk than the alternatives.

If I have to. Pragmatists who are not

enthusiastic about DMHT but see that it might be preferable to the alternatives (such as medication) or having no support at all (because of waiting times or accessing services in remote areas). It may be that this group would be most predisposed to finding fault with DMHT or stopping its use.

**OK then.** Users who are neutral on DMHT compared to alternatives, but are open to being guided by the HCP. They may not be convinced about DMHT, but will try it, but may also try other self-help approaches alongside the DMHT. This group may also experience a high level of drop-out, and may also assign any benefits to other sources, such as exercise.

I'm in. Users who are positive and either believe that DMHT will benefit them or are willing to 'give it a fair go'. They may already have used DMHT (for example a meditation app) making the approach familiar, and may be open-minded about the benefits of DMHT compared to more traditional forms of support. They are more likely to engage fully with the product, assign any benefits to it and potentially act as an advocate for it.

**Sign me up!** Technology enthusiasts who are very comfortable with innovation and digital products and have a sense of excitement of the benefits DMHT technology could bring. They are likely to be using DMHT already and have at least as much knowledge as the HCP, and are most likely to see the DMHT as helping and then recommending it to others.

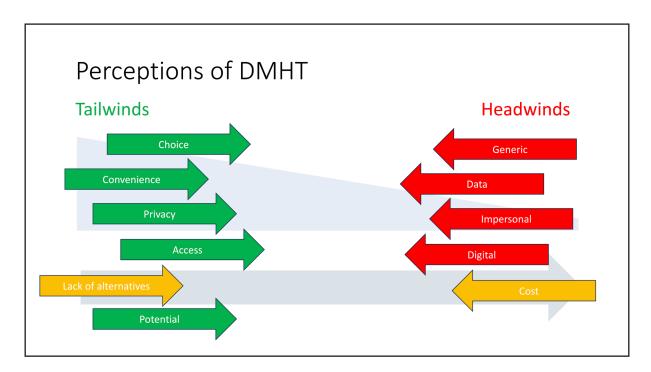


Figure 4: Examples of headwinds and tailwinds affecting the uptake of DMHT.

# 10.4 Behavioural Modelling

As with segmentation, it is hard to model behaviour with confidence using only qualitative evidence. But there are some elements we can draw out which could inform a more fully-developed theory of change. For example, we found a number of factors that might encourage someone to use DMHT and others that would discourage them. (We have used the terms 'tailwinds' and 'headwinds': they are sometimes referred to as motivators, drivers or barriers). These would vary in intensity and relevance for each individual, and for each group of individuals, but would also reveal patterns which could be addressed through the design and use of DMHT, and how DMHT is communicated, and so inform the regulatory regime. These are illustrated in Figure 4.

It is striking that many of the tailwinds and headwinds are conditional on other factors. For example, the additional privacy offered by DMHT is a driver; but it is conditional on DMHT having proper protection for personal data; without this, the desire for privacy becomes a headwind or barrier to uptake. Similarly, cost is a headwind because it limits people's choice of apps; but paying for a DMT product is also seen as providing some reassurance about quality, and so is also a tailwind. This reflects both the wide range of DMHT products and potential uses, and also the fact that most people do not have rigid views about DMHT: they are still considering the pros and cons for themselves.

## 10.5 Future Research

Given that this project has explored an area which is both new and complex, it is no surprise that there are issues which would gain from further research. These include:

- A quantitative survey, either of the public as a whole or of users and potential users of DMHT, which would be an opportunity to test the extent to which the attitudes expressed by participants were representative of the population as a whole, and also to provide data for segmentation and behavioural modelling.
- Research with healthcare
   professions, who are critical
   intermediaries between the public
   and DMHT products. Their attitudes
   and behaviours are likely to provide
   critical in helping the public to
   develop their understanding of the
   risks and benefits of different forms of
   DMHT.
- Ethnographic research to observe potential users as they go through the process of selecting and trialling DMHT products, to understand more about their real-world decisionmaking and lived experience.
- Research on DMHT and specific conditions. Some mental health conditions are less common (for example, psychosis compared to anxiety) and so we had few participants with lived experience within our sample: yet many of these conditions are also higher risk,

particularly because the research identified that these might be underserved, or inappropriately served, by existing products. These low-incidence/high risk areas for DMHT use may be particularly challenging to regulate.

- Testing or co-developing guidance. Involving patients in the development, design or finalising of guidance will help ensure it both meets their needs and is effective in communicating key concepts such as risk and consent.
- International context. DMHT are generally accessed through global platforms, which complicates public expectations and the regulatory framework. Further, the UK plays a leading role in healthcare regulation and an international study could establish the extent to which this research and potential responses in the UK could contribute to international health objectives.

# Annex: Lived Experience

The one-to-one depth interviews allowed participants to explain in more detail their own experiences with DMHT. These help illustrate the real-world use of DMHT product types (and for this reason we have not identified specific products by name.)

"It's a journal app that acts like a physical diary but on my phone. It's really simple. I type in each day and it saves it for later reference. I got recommended it on the app store when I was looking for it. There are no ads or extra features. You can't put in images and no-one is giving advice or guided meditation tips. If it bugged out and crashed I would report it to the developer, but nothing in it could do any wrong. I still use it. I guess I would recommend it to friends... I would recommend journaling as a method rather than this app. I'm sure there are plenty of others too."

"I can't remember the name. It was recommended by a friend. You set goals and breathing techniques and things about gratitude and motivation. There are 'to do' things and a mascot thing to motivate you. My mental health improved and I felt better. It was helpful to set really small goals, though it didn't help with helping me talk to people or with my confidence. It was more catered to more severe depression than I was experiencing. It wasn't exactly what I needed but it did help to some extent. I Stopped because it had helped me as much as it could. I don't know if it was regulated. I think it said it was approved by a mental health professional. I had no concerns on the content."

"My mum told me about it. It works OK and has a good variety of things. It's free to download and works fine without the premium upgrade. If someone asked, I would recommend it. There are groups where you can talk to other people. It can go wrong, but if you try to send something like a swear then it won't let you send it. You can report things to the developers if there's a problem and

also I'd tell my mum if I got worried. I used this for background noise to get to sleep. Now I listen to music, but not against using it."

"Whenever I'm sad or angry I write a story on the app specifically to help me calm down and to deal with my emotions. I was looking for apps where I was able to write my emotions and searched for it on the app store. It's free to use. There's nothing I dislike. It doesn't give any advice. If you have a problem, there's an email you can contact people and ask them to sort out the problem on the app. I still use it. The benefit is I get to look back on all the stories when I'm angry or sad and reading them back helps show me how I've gotten through it."

"My parents paid for teen counselling on a website. It was really useful and accessible. When my mental health got so bad I did have to tell them and they just paid for it. It helped me talk through problems and coping mechanisms and it got a lot better. If there was a problem – if I didn't like the therapist I was able to get transferred to another person."

"It was easy to access the website but I didn't have a positive experience. It took forever to speak to someone and I didn't find it helpful. The advice was so basic and reply times too long. I stopped using it as it wasn't helping me. It forced me to talk to family and friends and caused me

to open up."

"I used it during exams as I had struggles sleeping. A friend shared their log-in with me so I could use it. I didn't ask permission from my parents. The sleep meditation I found helpful. I don't have the app anymore, but I didn't feel the need to use it anymore – my anxiety was just around exams. But if I struggle to sleep I'll think about what it taught me."

"The app had a simple layout and was easy to use, with ambient sounds and softly speaking voice instructions. I found the guided meditation effective in helping me relax and calm down before bed. I used the app once a day, mainly before going to sleep. I saw the app as a meditation tool and believed it provided different benefits compared to faceto-face appointments with healthcare professionals. I did not have any major dislikes about the app, although I found it difficult to follow the voice instructions at times. I think an app like this is quite different from therapy or professional support."

"When you self-harm or have any type of addiction, like smoking or vaping or anything like that, the app keeps track of how long you haven't been doing that thing for. It motivates you and gives you milestones, like eight months off not doing something. There's another app I use that's a worrying app, where you tell your worries to a worry doll and it's

meant to take the worry off you and get it off your head. It sends you notifications to make sure you're okay and things like that."

"I was referred to this app by my health app. I looked at the reviews and it seemed quite good, especially all the features. It also recommended the sleep tracker app and that stood out to me as a nice way to track my sleep. I have a smart watch, but I thought I could compare it and see if it's accurate. It gives me information on how I am during the night, if I'm snoring etc; and if there's any worry about my sleep and what I could do. The sleep tracker even recommends me ways I could keep calm at night, meditation music, sleep stories, sleep sounds - just generally stuff that helps you stay calm – that's generally linked to my mental health, and my feelings and balancing my stress and emotions."