Written evidence submitted by NIHR MindTech MedTech Co-Operative, University of Nottingham (CYP0114)

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1. Introduction

1.1. NIHR MindTech Mental Health MedTech and In-vitro diagnostic Co-operative has been active since 2013, working in partnership with healthcare professionals, patients and the public, researchers and industry to identify unmet needs and support the development, adoption and evaluation of new technologies for mental healthcare.

1.2. The Nottingham Biomedical Research Centre Mental Health and Technology Theme (MH&T BRC) is also NIHR funded, with a focus on developing the next generation of technologies with the potential to transform the lives of people with mental health difficulties, improve healthcare delivery and stimulate the UK economy.

1.3. MindTech and the MH&T BRC are recognised worldwide for their high-quality research and expertise in the area of digital health interventions (DHIs) developed and designed for children and young people's mental health (see Appendix for publications).

1.4. Many education providers and children and young people's mental health services have moved to online delivery or begun to offer more digital interventions during the pandemic. Looking to the future it is unlikely that these will be rolled back as the expected rise in mental health needs, along with the closure of many third sector providers, will lead to an increased demand on services.

1.5. We are concerned that the speed of this shift towards mental health DHIs has meant that children and young people, and their carers, have been excluded from decisions and that evidence of efficacy has not been appropriately scrutinised leading to interventions and delivery models that may not be fit for purpose.

1.6. This summary of evidence highlights both published research (see Appendix) and brings together the insights of researchers working across MindTech and the MH&T BRC who have multidisciplinary experience of this area.

2. Summary of key recommendations

2.1. A review of how providers of children and young peoples' mental health have adopted and evaluated DHIs during the pandemic should be conducted to highlight evidence of best practice and recommend ways that DHIs can be better utilised.

2.2. Children and young people, along with their carers, must be involved in the planning and delivery of DHIs within mental health services. From design, through research and into adoption, there must be an increase in investment to ensure that their needs and priorities are met. Hard to reach groups should be better enabled to participate through national initiatives.

2.3. Funding should be provided to develop an agreed taxonomy for mental health DHI research so that evidence can be more easily collated and showcased.

2.4. National bodies that already play a role in standardising and regulating children and young peoples' mental health services should be encouraged to invest in bringing together guidance and curated libraries of effective DHIs.

3. The wider changes needed in the system as a whole

3.1. The evidence clearly shows that DHIs can be effective at improving mental health outcomes in children and young people (CY&P) across a range of conditions. However, research has typically highlighted gaps where their effectiveness has been challenged:

3.1.1. C&YP often report low levels of engagement with DHIs

3.1.2. DHIs are mainly developed to address anxiety and depression, meaning that evidence for other conditions is scarce

3.1.3. There are few studies that specifically target younger children, those who do not engage in school or are often absent, and those with known mental health risk factors

3.1.4. There is very little research that directly addresses how DHIs can be implemented

3.2. Within practice, our work with providers has also demonstrated that the use of DHIs within C&YP's mental health may also be challenged at the level of delivery:

3.2.1. Services and clinicians have reported finding it difficult to identify what elements make up the “gold standard” for DHIs. Although there are frameworks available these often rely on clinicians to have some level of technical knowledge.

3.2.2. Services and clinicians may offer recommendations of DHIs to C&YP that have been identified through curated app libraries or personal use, yet few if any of these follow NICE guidelines or are CE marked.

3.2.3. Although research may have been conducted in specific settings there is little available to inform providers on how interventions can then be deployed across different settings.

3.2.4. The pandemic has highlighted the significant divide between services that were technology-enabled and those that weren’t, leading some to adopt DHIs that were not fit for purpose.

3.2.5. Even before the pandemic there was concern, and this has also been recognised within research, that not enough is known about the potential adverse events and negative outcomes associated with DHIs for C&YP’s mental health.

3.2.6. Providers may not have the training or competencies necessary to deploy DHIs within mental health. However, it is also unclear what these may be.

3.3. Our work with children, young people, and their families and carers has emphasised how important it is to include them within research and the delivery of DHIs.

3.3.1. The UK is still faced with a digital divide between the haves and the have nots; this is also relevant in younger generations, even though they may be seen to be more digitally proficient.

3.3.2. It is presumed that as digital technologies are increasingly used that knowledge in important areas such as security and privacy will increase exponentially. However, as this knowledge increases so too does the knowledge of how to overcome those protections. This is exacerbated by long and convoluted terms of use and terms of use that are not designed for younger people and their carers.

3.3.3. It is also clear that many young people do not know what DHIs are available for their mental health or how these might benefit them.

3.3.4. There is limited academic research on how to engage younger children in DHIs, along with their parents, despite the opportunities that are clear in delivering mental health interventions digitally at an early stage.

3.4. Working with industry, including SMEs and charities, has provided us with insights with regards the challenges that they face when investing in the development and retailing of DHIs for C&YP. Many of these exist more broadly than just within C&YP.

3.4.1. It can be difficult to ascertain the best path to deployment for clinically evidenced DHIs as C&YP's mental health services are delivered within educational settings as well as within the NHS.

3.4.2. Businesses face a significant cost regulating DHIs as medical devices and so may be more reticent to identify them as such, or may bring their products to other markets.

3.4.3. Within the UK there have been significant changes to how DHIs are standardised, regulated and assessed in recent years e.g. the introduction of Digital Technologies Assessment Criteria, changes to MHRA regulations due to Brexit. These are barriers to industry investment in the UK market.

3.5. The full potential of DHIs within C&YP's mental health treatment and management is unlikely to be realised unless there is an increased focus on how to translate research into practice. Our research and work with industry has found that evidence-based DHIs, many funded by public monies, are often not adopted into the national health service. There are several barriers we have identified:

3.5.1. Researchers do not consider, do not have the expertise, and/or do not have the funding to monetise or implement DHIs once clinical trials are complete.

3.5.2. Multidisciplinary stakeholders often do not work together to ensure that delivery models are developed for the most effective deployment of DHIs. This is particularly significant given the complexity of mental health provision for C&YP.

3.5.3. There is a lack of technical infrastructure (e.g., hosting platforms) to enable DHIs to be made available to C&YP.

4. Examples of best practice, including from other countries

4.1. Lumi Nova[1]

4.1.1. BfB Labs worked in partnership with Anxiety and Depression in Young People Research Clinic and MindTech, with funding from the NHS Improvement's SBRI Healthcare programme, to develop an engaging mobile game to help 7-12 year olds overcome anxiety using an evidence-based therapeutic intervention.

[1] https://www.bfb-labs.com/luminova

4.1.2. They used a user-centred design, involving children and their parents from the initial stages of development.

4.1.3. An independent early evaluation study found the app safely benefits children experiencing mild to moderate difficulties with anxiety

4.1.4. They are now the first paediatric mobile game for anxiety to receive regulatory approval from the UK Medicines and Healthcare Products Regulatory Agency.

4.2. American Psychiatric Association App Advisor[2]

4.2.1. Experts within the American Psychiatric Association (APA) worked together to develop a mental health app evaluation framework.

4.2.2. The APA now provides guidance for psychiatrists and other mental health professionals on how to use the evaluation framework to select apps for their own and their patients' use.

4.2.3. The APA also includes a sample of apps that have been evaluated.

4.3. SPARX[3]

4.3.1. SPARX is a computerised self-help programme that helps 12-19 year olds with mild to moderate depression using cognitive behavioural therapy (CBT) and game play. It was developed by researchers at the University of Auckland.

4.3.2. It is named as an example of digital CBT within NICE guidance NG134 for depression in C&YP yet it has neither been tested nor is it available within the UK.

4.3.3. It has been funded nationally within New Zealand under the Prime Minister's Youth Mental Health Project so that it can be accessed for free.

4.3.4. Researchers around the world are adapting it to local needs e.g. different cultures, different languages. MindTech is working with the University of Auckland to adapt and trial it within the UK.

4.4. ORBIT[4]

4.4.1. The Online Remote Behavioural Treatment for Tics project evaluates an English version of a therapist-guided online behavioural intervention ('BIP TIC') for children with tics developed by the Karolinska Institutet in Sweden.

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[2] https://www.psychiatry.org/psychiatrists/practice/mental-health-apps

[3] https://www.sparx.org.nz/

[4] https://www.mindtech.org.uk/research/research-themes/digital-interventions/orbit

4.4.2. MindTech translated the original intervention and are working in partnership with Great Ormond Street Hospital and Karolinska Institutet to evaluate the intervention in England thanks to funding from the NIHR Health Technology Assessment programme.

4.5. What's up with everyone?[5]

4.5.1. 'What's up with everyone?' is a collaborative project between the MH&T BRC, the Mental Health Foundation and Aardman to increase mental health literacy and awareness among young people.

4.5.2. Five short animation movies and accompanying materials were co-produced with young people to ensure that they were engaging and relatable.

4.5.3. All resources were scrutinised by young people.

4.6. ProReal[6]

4.6.1. ProReal is an immersive platform that helps users create visual representations of their experiences to explore different perspectives and solve problems alongside trained professionals either online or face-to-face.

4.6.2. The company, supported by MindTech, worked with Oxford Health NHS Foundation Trust to develop a Global Digital Exemplar Blueprint during the platform's trial within several Child and Adolescent Mental Health Services to build on previous research success and, by blueprinting the journey, enable other NHS Trusts to deliver new models of care using ProReal.

4.6.3. A Global Digital Exemplar Blueprint provides resources and information to support the implementation of digital technologies within NHS services.

4.7. #chatsafe[7]

4.7.1. Many countries have developed media guidelines for how to communicate safely about suicide but, as young people increasingly use social media to communicate, there is a need to provide guidelines that help young people to communicate safely online about suicide.

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[5] http://www.whatsupwitheveryone.com/

[6] https://www.proreal.world/

[7] https://www.orygen.org.au/chatsafe/Resources/International-guidelines

4.7.2. The #chatsafe guidelines were developed by Orygen, the National Centre of Excellence in Youth Mental Health in Australia, using the Delphi consensus methodology drawing on expert opinions from suicide prevention experts and a panel of young people.

4.7.3. Researchers in other countries have adapted these guidelines to local contexts e.g. different languages, different cultures.

4.7.4. Orygen are now evaluating the success of their campaign to raise awareness of these guidelines.

5. Measures to tackle increasing rates of self-harming and suicide among C&YP

5.1. We have worked in collaboration with Samaritans and other partners to co-produce guidelines[8] to enable young people to contribute to online content and communicate online in a safe way about self-harm and suicide. These build on the excellent work of Orygen in Australia who developed the #chatsafe guidelines.

5.2. Many young people won't seek help from clinical services so social media and online platforms can play a role in providing information, connection, validation and support.

5.3. However, there is the potential for harm. Online platforms have a responsibility to address the issue of harmful content but can also work with their users directly to ensure that there are safe, supportive and appropriate spaces and ways to share self-harm and suicide related content.

5.4. We worked with Samaritans as part of the Online Harms project to ensure young people with lived experience of self-harm and suicide who are likely to access and respond to this type of content were enabled to participate in workshops to co-produce guidelines.

5.5. Onset of the pandemic led us to move the workshops to an online format.

5.6. We developed safeguarding processes and procedures to ensure the young people contributing to the project felt safe and listened to.

5.7. The online format of workshops gave young people the chance to share through talking as well as writing. The young people felt involved and valued.

5.8. The young people provided actionable inputs that led to significant changes within the resources produced. They also felt that resources like these are needed in online spaces and felt that they were useful and usable.

5.9. Resources have now been launched by Samaritans. This shows how resources around self-harm and suicide can be developed in consultation with young people online and reinforces

[8] https://www.samaritans.org/news/samaritans-launch-new-online-resources-safer-internet-day/

that young people welcome the opportunity to talk about and share their expertise around self-harm and suicide. None of the young people reported any distress throughout the entire process.

5.10. Feedback from young people demonstrates how co-production can be safely enabled online in a way that is engaging, productive and positively received even when tackling sensitive topics.

5.11. We are now sharing practice and learning around involving young people in sensitive mental health projects and research with others via a special interest research group for Young People's Involvement in Digital Mental Health (YPii_DMH).

6. Conclusion

6.1. DHIs clearly have a lot to offer within children and young people's mental health. However, it is important to ensure that those provided are fit for purpose considering the many challenges found within research and adoption.

6.2. We have highlighted several areas within development, research, clinical practice, industry and use that are key to the successful adoption of effective DHIs within children and young people's mental health.

6.3. We have also outlined several projects, completed and ongoing, that demonstrate ways in which DHIs can be developed, evaluated and implemented here in the UK and other countries.

6.4. Our written evidence is based on high quality research and our multidisciplinary experience within this area. We believe that our recommendations can help to ensure that DHIs within children and young people's mental health provision are fit for purpose.

7. Appendix

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