YPii!

Young **P**eople's *i*nvolvement *i*n **D**igital **M**ental **H**ealth

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Welcome to the very first YPii DMH newsletter!

Working together with academics, policy makers, industry partners and young people we have been lucky enough to be given support by Emerging Minds to build on these collaborations and networks as part of a special interest research group (SIRG). It is the mission of YPii_DMH to involve young people in the way that mental health services are developing and adopting digital technologies, especially as the pandemic not only impacts on young people's mental health but moves many of the services online and into the digital sphere. YPii_DMH aims to ensure there are more opportunities for young people to be involved in digital mental health research through events, networking and bringing together best practice resources for others to access. The YPii_DMH SIRG will elevate and amplify the voice of young people within digital mental health through events like Ideathons where their experiences and needs will be put front and centre.

Introductions

This is a place for members to share a little about themselves.

[MindTech](#) are NIHR funded and tasked with supporting the development, evaluation and adoption of digital technologies into the NHS. Whilst working with Samaritans during the pandemic to engage young people in co-producing their Online Harms guidance on how to communicate safely about self-harm and suicide online, MindTech research fellows, Dr Aislinn Bergin and Dr Joanna Lockwood, realised that whilst there were many groups across the country engaging and involving young people through new technologies there was nothing that brought them together. The call from Emerging Minds at the end of 2020 to set up special interest research groups offered an opportunity to build more collaborative networks in the area of young people's involvement in digital mental health.

We hope that YPii DMH can offer young people more opportunities to be involved in high quality digital mental health research through creating more spaces in which young people can share their expertise and knowledge with stakeholders. By sharing learning across disciplines and involving those with lived experience we can better understand how to safely and effectively engage young people in the development and delivery of the services and interventions that they use.

We are a group of approx 60 Young People interested in driving the agenda for digital mental health across Greater Manchester and the UK. The group is coordinated by the GM Digital Research Unit at Greater Manchester Mental Health / University of Manchester. We have an active digital mental health training and development programme for all young people volunteers who join our weekly groups. We also run a Digital Navigator programme for young people interested in implementing digital mental health solutions within Greater Manchester Mental Health NHS Foundation Trust. Find us [here](#).

Nottinghamshire University Hospital NHS Trust Young Person Advisory Group

We are the Nottingham University Hospitals NHS Trust, Research and Innovation, Young Persons Advisory Group (YPAG). Our group has around 20 young people aged between 8 – 18 years old. Some of us have experience of taking part in health research, or have experience of living with a health condition.

Many of us are interested in learning more about medicine/research/science, with a view to maybe having future careers in one of these areas. All of us want to help researchers to improve the delivery of health research, particularly research which aims to involve children and young people.

[Kooth Digital Health](#) have been supporting children and young people across England and Wales for the past 15 years through accessible online mental health support. We aim to work alongside service users to provide effective and compassionate support. The research team at Kooth are constantly evolving and exploring how to better involve both service users and non-service users in their work in a range of roles. We care about what matters to our services users, not what is the matter with them. It is with this interest at heart, and the desire to learn from both peers and experts by experience that we are involved with the YPii DMH. We hope to offer our experience and best practice, while working alongside others, to develop ethical, inclusive, and collaborate ideas for co-design, co-production, and broad involvement of young people.

YPii Spotlight

This is a place where we can spotlight the work of our members.

We hope that in coming newsletters you'll take the opportunity to share your practice and experiences of involving young people in digital mental health - or your expertise and insights as a young person engaging in digital mental health involvement opportunities - in the YPii Spotlight section of the e-newsletter. This is a place to start conversations, ask questions, offer insights and reach out to others who share your interest in building opportunities for young people to be meaningfully involved in designing, developing and discussing digital mental health. We have much to learn from each other as we navigate this vital and interesting sphere.

In our first newsletter, Dr Jo Lockwood from our coordinating team shares some of her thinking around a recent online co-production project that was done alongside her colleague Dr Aislinn Bergin and commissioned by Samaritans as part of their Online Harms programme of work.

My own research focuses on self-harm and suicide in young people, and I have often needed to reflect on, articulate and challenge reasoning about why we should be openly talking about these sensitive issues with young people and actively involving them in this field of research. Studies consistently show that asking young people about self-harm and suicide in research contexts does not cause distress, induce or increase risk of these behaviours and can be

beneficial, particularly for those who may have lived experience. Such knowledge is important to reference in our ethical decision-making as researchers and it is our duty to make sure we are not closing down opportunities for young people to contribute to research, but rather creating safe spaces in which they can be heard, respected and meaningfully involved. Failure to involve young people with lived experience as partners is also a wasted opportunity to create relevant, targeted research and outcomes with better translational impact. This benefits us all. But there are of course additional ethical challenges associated with such participatory work online.

Project Overview

We invited young people (18-25 years) with lived experience to two interactive online workshops where we discussed self-harm and suicide-related content and safety in the digital world, working through draft resources and sharing suggestions about how to make sure the scope, messaging, tone and look of these resources felt right.

Ethical Touchstones

Relevance… We needed to involve young people for whom the co-produced content had relevance, those with lived experience of self-harm or suicidality or who had supported others with lived experience so that the messaging would reflect their voice and opinions.

Measurable and impactful… We needed to ensure that their contributions were listened to and had impact on the resources created.

Duty of care… We needed to balance enabling young people with lived experience of challenging mental health issues to be involved in co-production and consultation work about sensitive issues, with a primary duty of care to safeguard and support those young people, while every step of the process (from design, development, recruitment, to running the workshops, feedback and follow-up) was taking place remotely online.

What we did

- We gained ethical approval to proceed as an involvement project at the University level, before completing institution-level ethics review (Samaritans) and completed our own internal involvement review process at MindTech through our own PPI team. Expert PPI advisory groups and young people helped us draft all our processes and materials providing information, consent processes, contact preferences, safeguarding, debriefs and feedback.
- We produced a comprehensive Project Support plan and risk protocol, reviewed with stakeholders and PPI members, to prioritise the safety of young people. In this we set out our contingency planning, for example steps to take if someone left the workshop.
- We took extra time to get to know everyone by increasing phone calls and emails, careful to balance this extra burden with building more rapport, and provided opportunities to check-in, troubleshoot, feedback and ask questions. We ensured everyone understood the project and that those involved were not distressed.
- We worked with expert partners. Harmless (a user-led service) supported our recruitment. Their counsellors were on hand during and immediately following the workshops (in separate break out spaces) to offer support if requested. We worked with mHabitat (experts in co-design and digital inclusion) to facilitate our workshops,

ensure content and discussion was recorded, move young people into rooms and spaces, and take care of the tech. This meant Aislinn and I were free to observe, check on participants and follow the safety protocol if necessary.

- We used tools like MURAL and Zoom to make the workshops interactive which worked well on the whole, but we made sure we gave young people a chance to practice with these beforehand and linked everyone to mHabitat partners to troubleshoot tech if necessary.
- We thought about the number of partners and young people on each call, careful to balance the power dynamic. Everyone was introduced, all roles were clear.
- Our workshop sessions were 1.5 hours in duration. This included time for introductions and ice-breakers, the establishment of shared ground rules, final interactive activities to recalibrate mood and a quick mood capture rating. Our sessions were very structured with pre-determined activities and well-defined tasks, communicated at the start. Young people told us this worked well and helped when dealing with sensitive content.
- This was not a tokenistic involvement. Our offer to young people was to contribute to important national conversations about suicide and self-harm by taking part in a project with demonstrable outcomes… actual content that would be delivered online. We followed INVOLVE principals; each young person was paid for their time and we offered everyone multiple chances to feedback on the process and the content, to sense check the final outputs and to be involved in further dissemination and related campaign work.
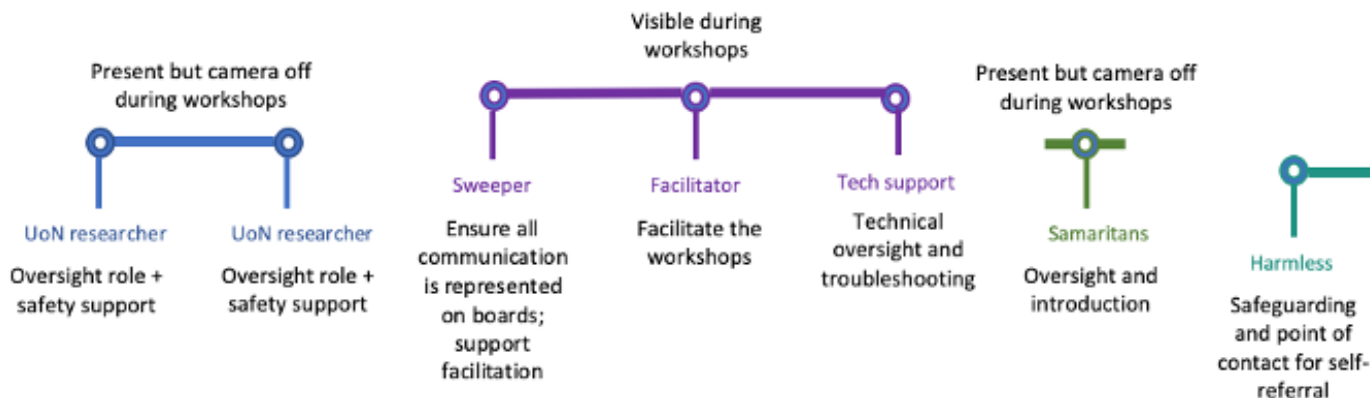
Project team present during workshops

What we learned

Most participants indicated that they didn't have any technical difficulties that needed additional support. However, internet connections were patchy in some cases. Not everyone took the opportunity to practice with the technology beforehand. Our group were largely comfortable with technology however (and were recruited on the basis of familiarity being in digital spaces). Those that did valued the opportunity. Young people told us after the first session that they welcomed encouragement from the facilitator to get involved and wanted more ice-breakers so we stepped this up for session two. They welcomed too the flexibility to respond verbally and in writing to activities. Having a Sweeper meant that young people

could choose to populate a post-it note on MURAL, or simply speak their thoughts and have the sweeper capture them. We provided additional reinforcement in our second workshop that we valued either form of expression.

This was a successful project in which young people were comfortable and supported to discuss sensitive content around self-harm and suicide. There were no safeguarding issues. We share our reflections on this process with a view to opening discussion and sharing learning.

Caoime (18) shared her experience of working with us to co-produce the materials.

"I really appreciated the opportunity to be involved in something like this as it has the potential to make a difference to so many people's lives. It was great to work alongside other young people and I felt that the whole experience was really positive."

News, Views, Reviews

[Creating spaces for children and young people's voices in mental health research and services during a pandemic](#)

Read more about the work that Jo and Aislinn have done along with some highlights from the rest of the collaborating team.

[Immersive virtual reality and digital applied gaming interventions for the treatment of mental health problems in children and young people: the need for rigorous treatment development and clinical evaluation](#)

A recent review highlights the importance of involving children and young people, along with their carers, in the development and evaluation of mental health virtual reality and serious game interventions.

Youth Coordinator Champion

We are currently recruiting for a Youth Coordinator Champion to join us and are looking forward to sharing more once they are in post.

Have you got something to share?

Please do get in touch with us with your subject heading indicating which part of the newsletter you would like to contribute to with suggestions of news or upcomg events. We are welcoming our members to provide an introduction of themselves, their groups and/or research. Please complete [this](#) form if you are interested. If you would like to be considered for our spotlight please let us know if you will be sharing ongoing or completed research, how-to guides, case studies and testimonials, interviews with experts, or other important pieces of learning in a short summary (under 250 words). The YPii Spotlight is under 1000 words but can link to more information if needed.