

YPii!



Young People's involvement in Digital Mental Health

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YPii it's Dragon's Den!

We are so pleased to have been able to host a Dragons' Den for young people and researchers to come together and discuss a range of different projects, from furry robots to mental health apps. On Zoom one early evening in May, four fantastic young Dragons joined us from across the world along with four researchers (including PhD students and Professors). We are so fortunate that the funding from Emerging Minds meant we could compensate the Dragons for their advice and time whilst providing this incredible opportunity free to researchers – although clearly it couldn't stretch to monetary investment for the projects, just the real value of young peoples' experience and expertise. Each of the pitches had the chance of a 100,000 pretend pound investment from each of the Dragons with the top project earning an impressive 360,000 pretend pounds! We are even more delighted that the Dragons felt that we helped young people to have their voice heard and helped researchers hear from young people. It is that kind of thing that makes all of the hard work organising an event in your spare time worthwhile! The Dragons also rated the communication before the event and the event itself as good or very good.

The Dragons and researchers thought it would be useful to have more time for discussion and we agree! The chance to hear from the Dragons and discuss projects with them was key to the event's value. For next time we will consider whether we ask researchers to do shorter pitches or if reducing the number of pitches might provide more time for discussion...

All of those who responded said they would be interested in taking part in a similar event again which is great to hear. We are so grateful to the Dragons who shared their thoughts with us, there were also some great suggestions about changes we could make and some lovely feedback about the event from the researchers.

This was our first Dragons' Den, but it won't be our last! It was exciting to bring researchers and young people together to discuss research as a core aim of our network. We are going to bring our learning from this to the rest of the YPii_DMH coordinating team, put our heads together and work out what we can do next time. Do let us know if you have thoughts or suggestions too.

So, watch this space – there be dragons!

YPii Spotlight

This is a place where we can spotlight the work of our members, whether that is research, case studies or guidance.

This week Charlotte Mindel, Research and Evaluation Lead at Kooth Digital, shares some of their learnings from involving young people in their research. [Kooth](#) is an online mental wellbeing community that offers free, safe and anonymous support.

At Kooth we're privileged to have both a research team and tens of thousands of users who might want to get involved with our work. Despite this, there are so many challenges when it comes to patient and public involvement (PPI) in research that aren't mitigated simply by having 'access' to young people. As a service, safety and our duty of care must come first, as a research team we recognise the power and importance of the young person's voice in our research.

Last year we found ourselves a unique position when the pandemic hit, as an already-digital company there was little about the service model and infrastructure that required changing to facilitate lockdown restrictions. We've used this position to run a study understanding more about the experiences of vulnerable young people during the Covid-19 pandemic, a group for whom it was hypothesised, and have been shown to be at risk of experiencing detrimental circumstances as a result of lockdown. Given the real-world challenge of doing research during an ongoing pandemic we focused the qualitative study on the mediated insights offered through Kooth practitioners. They brought their experience, training and expertise to the insights that they were able to share with us about the vulnerable young people within their case load on web-based therapeutic platform Kooth.

But this research is about young people, and the care of young people, and therefore, a subject that matters to young people. We needed young people to be involved to guide our thinking so this work could develop in line with what matters to them, and offer a greater depth to our reflexive approach. Before we got started we gained ethical approval for an expert group of young people to co-design and advise on the research throughout the study.

Collaborating with the experts

Given the aforementioned challenges of running PPI with service users, including their anonymous status on Kooth, we chose to collaborate with an organisation where the diverse representation of young people and citizen research is at their heart - Leaders Unlocked. We shared our group requirements with Leaders Unlocked:

- A group size of 10-12
- Ensure the group is made up of a diverse range of young people with lived experience of various vulnerabilities
- Young people could be anywhere in the country

Ideally, young people would have an interest in mental and emotional wellbeing

Our final group consisted of five females and six males aged 16 to 25 years, from a range of ethnic backgrounds (White 55%, Asian 18%, Black 9% and Mixed ethnicity 18%), and lived experiences.

What did involvement look like?

We ran three online workshop sessions with the group at different time points:

1. Prior to focus groups with practitioners
2. Mid-way through focus groups, after initial data analysis
3. Following all data collection and analysis

The workshops themselves were co-designed and jointly run by a research lead, and research assistant at Kooth, and a project manager, and a project assistant from Leaders Unlocked.

Workshops were 2-2.5 hours long, with breaks and were held on Zoom. Zoom enabled us to have young people in the group from all over the country, but running digital sessions does come with it's challenges. In order to engage the whole group and not lose anyone behind a digital wall there were a few key mechanisms we used:

- All the participants in the group were sent a pre-task of some description, usually to think about one of the big questions we were going to dive into in the session. For the last workshop they were asked to find a piece of research they had found really accessible and think about what made it so. This meant that there wasn't an overload of new information in the sessions, and everyone had a chance to consider their views on a subject or question before bringing it to the group.
- The sessions were split into a combination of whole group discussion and smaller discussions in break-out rooms. For the break-out room sessions, one participant could volunteer themselves as a note taker to share the discussion with the rest of the group following the break-out sessions. The responsibility and autonomy with the note-taker role was really well suited to some members of the group and meant there were opportunities to 'do more' than participate in the conversation.
- The group was really engaged, involving young people who have been part of participation groups previously so it often wasn't necessary to 'fill time' or even make the sessions overtly interactive. However, we did have some Zoom rules which meant everyone could feel at ease. These included being able to choose to have your video on or off, young people could take a break anytime they needed, and participants could choose whether they wanted to communicate verbally via audio setting or through the text-based chat. We found that generally participants were happy to remain on video and communicate verbally.

Workshop 1

The first workshop was about **exploration**. We explored what vulnerability means to young people, what their priorities would be for a piece of work such as the one we proposed, and whether the themes we had defined for the focus groups were comprehensive enough to capture the experience of young people.

We found that vulnerability is a complex word to define and really requires defining clearly, and also that defining vulnerability by the ten-item Adverse Childhood Experiences list is not sufficient to capture all those who might be vulnerable. We expanded our definition to include the suggestions from the group which influenced our eligibility criteria for young

people whose stories would be included by practitioners in the focus groups. From this first session it was also identified that we hadn't covered anything within our themes relating to the coping mechanisms of young people which was important to us and to the group, so we adapted the focus group schedule to include a question around coping.

Workshop 2

The second workshop was focused on analysis **interpretation**. We discussed the initial codes with the group to find out what resonated with them, and whether codes we had grouped together in our thematic analysis made sense to them and were accurate.

One of the important distinctions in this session was semantic - which is pretty critical to thematic analysis. There was a lot of discussion around the words loneliness and isolation, and the difference between physical loneliness and the feeling of being alone because you don't belong. This supported other conversations we'd been having as a research team as to whether to enquire more about the individual or collective experience of vulnerable young people. We took these ideas to explore further in the second two focus groups we ran.

Workshop 3

The final workshop was focused on **dissemination**. We explored how accessible research is to young people and what ideas the group had to make it more accessible. From this workshop we identified a number of ways the group would like to continue to be involved through writing blogs about the work, and getting involved with the participation network being set up by Kooth.

Reflections

The whole experience was invaluable to the work which is in the process of being written up for journal submission. Working with Leaders Unlocked and the group we had really opened up space for this work to develop, and has meant that the discussion and impact of the work is so much more meaningful than presenting professional opinion only.

Introductions

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

Jenny Ferguson, Operational Delivery Lead for Children and Young People at COSLA

Hi there, I have recently taken up a post as the delivery lead for the Scottish Government's Suicide Prevention Plan. Leading on the work of [Action 8](#) in the plan 'ensur[ing] that all of the actions of the Suicide Prevention Action Plan consider the needs of children and young people'. My background is in co-production and working with people to achieve change and this will be the approach used to drive this work. I am at the initial stages of this work firmly in the inquiry stage. I work under the National Suicide Prevention Leadership group in Scotland with all my work reporting into them and am hosted by COSLA so my work is aligned with both the national and local work ongoing in suicide prevention. I am looking forward to connecting in with the network and learning from other suicide prevention work. [Email](#).

Glorianna Jagfield, PhD student in the Spectrum Centre for Mental Health Research at Lancaster University

I'm [Glorianna](#), a third year PhD student in the Spectrum Centre for Mental Health Research at Lancaster University. My PhD project looks at personal recovery in bipolar disorder and how people with a bipolar diagnosis talk about recovery in public posts on the social media platform Reddit. I combine quantitative and qualitative methods from health research, natural language processing, and corpus linguistics. Social media data allows to study experiences of people who haven't been taking part in more traditional health research studies, including younger people. This research has the potential to contribute to improving the lives of people living with bipolar: For example, getting more insight into what helps or hinders personal recovery yields starting points of how to improve mental health care to best support the priorities of people with a bipolar diagnosis. Also, getting a better grasp around the language that people living with bipolar use to talk about their recovery or living well can lead to mental health professionals and information materials covering these issues more accessibly. At the Spectrum Centre we're committed to conducting research in line with the priorities of people living with severe mental health issues. Therefore, we take their feedback on board as much as possible, for example via an advisory panel of volunteers with lived experience of psychosis or bipolar disorder facilitated by our service user researcher. Please get in touch if you've got any comments or would like to know more about my project – either via [email](#) or via Twitter [@glorisonne](#).

News, Views, Reviews

[New NIHR Guidelines for CYP Involvement in Research](#)

These guidelines, published in April this year, update NIHR guidelines on involving children and young people as advisors in research. Very useful top tips and clarity on areas including confidentiality.

[Lundy Model of Participation Resources](#)

A framework and selection of resources to evaluate and assess meaningful participation of CYP in decision-making.

[Zinc Venture Builder Programme: Improving the Mental Health of Children and Young People](#)

Starting in October this is a full-time year-long programme to build startups that tackle social challenges. They will be tackling CYP mental health this year and are looking for researchers, clinicians and other stakeholders interested developing solutions. Keep an eye out for their meet and greet events.

[Co-developing a Mental Health and Wellbeing Chatbot With and for Young People](#)

This open-source paper outlines the co-production process that the researchers engaged in with their Youth and Expert Reference group in the development of a mental health chatbot using AI.

[Implementation lessons from the transition to telehealth during COVID-19: a survey of clinicians and young people from youth mental health services](#)

This study explored how young people and clinicians felt about the move to telehealth during the pandemic. Whilst young people were positive, interestingly clinicians felt it had negatively impacted on their ability to deliver their services.

[Institute of Mental Health Research Day, University of Nottingham](#)

This year all of the presentations were recorded and are currently available online. Several cover the involvement of young people in digital mental health including the winner of best presentation, our very own Dr Jo Lockwood who presented “Immersive gaming technology to mobilise evidence-based interventions for childhood anxiety – learning from an evaluation of the Lumi Nova app”.

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 upcoming 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.