Designing resources to support young people's mental health

Emerging Minds

The aim of this research briefing is to highlight some of the ways design is contributing to mental health research

This briefing stems from the Emerging Minds cross-disciplinary research network, funded by UK Research & Innovation. The network aims to reduce the prevalence of mental health problems experienced by children and young people

This briefing summarises the contribution that design-led research can make to understanding, explaining and supporting young people's mental health.

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This briefing includes references to papers where design thinking and methods have been used in research about young people's mental health.

The appendix provides a link to a table with summaries of additional resources.

What do we mean by design-led research?

Design-led research begins with an open question and ends with a proposal or a deliverable that is appropriate and useful to stakeholders.

Research is open, collaborative and explorative

Projects often involve several groups of users or stakeholders who bring ideas and issues from their experience.

Design practice and research drive the project

Designers act as facilitators and community builders. Methods and approaches taken from design, such as workshops and prototyping, are used to develop ideas raised by stakeholders. Designers like to ask open questions to avoid fixed outcomes, ideas and definitions. This ensures each participant is able to contribute.

The process produces meaningful outcomes

These outcomes include resources, services and products that are centred around the needs of the user. They are driven by the process rather than determined in advance.

Design-led projects

Create knowledge by learning about lived experiences of children and young people, which stimulates empathy and trust. Collaborating with service providers, researchers and users provides tangible insights into the possibilities of and challenges to service provision.

Transform knowledge into resources that are appropriate for the target audience. The deliverables for children and young people explored in this briefing include visual storytelling, computer or mobile phone applications and games.

Encourage those involved in a project to question their biases by encouraging them to imagine possibilities beyond their own field or experiences.

Methods and approaches

Defining, redefining

Open research questions and early scoping

Design-led research tends to begin with broad open-ended questions and relies on the process to guide the way. A common starting point for researchers is hosting exploratory workshops, where stakeholders collectively define a project's aims and values. Although expert interviews and desk research are common in design-led processes, they are not prioritised over building an understanding of users' wants, ideas, needs, desires and behaviours (Thabrew et al., 2018).

In a project exploring the scope of social and mobile technologies in remote mental health contexts, researchers began with the open question 'What is needed and what is possible?' (Orlowski et al. 2018). Two thirds of the project was devoted to workshopping this question, engendering meaningful participation and creative thinking. Their main outcome, a mobile communication tool, emerged only during the final phase of the project.

Creating shared definitions

Early phases of projects often seek to redefine language and concepts around mental health. This ensures all participants feel empowered to share their views and helps prevent miscommunication.

A research project exploring youth crisis began by asking young people to input words related to their experience of crisis and support into a shared word cloud (Hodson et al., 2019). This was displayed throughout the workshop to guide discussion. In exploratory workshops, another group of researchers asked the young participants to create a shared definition of 'wellbeing', with the aim of producing more relevant online interventions for young people (Winsall et al., 2019). A project engaging young people with schizophrenia supplemented language with images (called 'graphic facilitation') to create a shared form of communication that was equally accessible to the young people and to the project team.

Methods and approaches

Building an understanding

Capturing lived experiences

In mental health for children and young people, capturing experience is particularly important because there is limited literature available on specific audiences and contexts. In a project on young people's experiences of asthma, researchers hosted participatory design workshops that included collaborative collage-making on lived experiences (Peters et al., 2017). Before the workshop, they asked young people to fill in a workbook as a warm-up and sensitisation tool. The team reported that these generative activities helped them to understand the psychological experiences of children with asthma, which are often difficult to express.

One project team used a fictional character called 'Jack' to allow their group of young people to share personal thoughts and experiences around psychosis (Nakarada-Kordic et al., 2017). In their workshops with young people designing a suicide prevention campaign, another team avoided the more traditional persona method to avoid possible triggers, instead opting for 'detached' design personas in the form of stick figures without names, identifiable gender or ethnicity (Thorn et al., 2020).

Building an understanding of the context

Design research generates knowledge in different contexts and with different stakeholder groups. Storyboards and mapping are often used to better understand problems, needs and preferences (Terp et al., 2016). A literature review and interviews with service providers can be supplemented with community consultation sessions to gain a fuller picture of the challenges facing young people in crisis (Hodson et al., 2019).

Methods and approaches

Collaboration

With children and young people

Involving children and young people in envisioning and creating resources is central to design-led approaches. Research shows that young people's priorities often differ considerably from the ones clinicians consider to be important to them (Nakarada-Kordic et al, 2017).

A series of workshops on stress management strategies for teenagers showed a preference for resources that were uncluttered and based specifically around teenage activities (Bhattacharya et al., 2019). In general, resources that are personalised to different needs are more likely to be engaged with by young people (Powell et al., 2021).

Working with the same group over the duration of a project is beneficial. Many studies note the importance of repeated, meaningful engagement that influences the project at every stage (Nakarada Kordic et al., 2017; Powell et al. 2021; Gonsalves et al., 2019). Sustained engagement is also a valuable trust-building tool in the often sensitive contexts of mental health research (Larkin et. al, 2015).

With healthcare staff and clinicians

Successful projects evolve out of processes where designers and researchers work with open-minded clinicians and healthcare partners (Nakarada-Kordic et al., 2017). For example, the input of paediatric healthcare workers in developing a relaxation device for children undergoing medical procedures enabled researchers to create a machine that responded intelligently to the clinical setting, based on real situations rather than imagined scenarios (Morrow et. al., 2018).

Involvement in co-design processes can also be beneficial for healthcare professionals. While designing a website for young people with psychosis, one team noted how mental healthcare staff saw their own role shift from the role of expert to listener (Szücs Johansson et al., 2017). Another team observed how rural youth mental health professionals overcame the differences in their practice and were able to imagine shared future realities for mental healthcare (Orlowski et al., 2018).

Methods and approaches

Collaboration

Collaborative design

Collaborative or participatory processes involve the end user in the design process. This helps to establish social connections, creates a level playing field for the stakeholders and encourages multidisciplinary conversations.

Co-design can help people with severe mental illness to become 'active and strong collaborative partners' (Terp et al., 2016). One group of researchers, for example, co-designed games with young people with complex needs. During testing in schools, the games were found to be effective in supporting communication and promote problem-based learning (Hart et al., 2020).

When asking for non-designers to do the designing in the workshop, some capacity building is required. This might take the form of design training (Larkin et. al, 2015), asking participants to prepare thoughts or ideas to bring to the workshop (Winsall et al., 2019) or holding a briefing in the theoretical and practical aspects of service design (Szücs Johansson et al., 2017).

Creating safe collaborative environments

Researchers must ensure the wellbeing of participants in co-designing sessions with children and young people who have experience of mental health issues. This could mean including a wellbeing officer or creating spaces for private discussions, feedback and time away from the group (Whitham et al., 2019).

Providing a safe workshop environment is essential to produce successful outcomes Thorn et al. 2020). One group of researchers ensured comfort by providing sensory toys and mindfulness materials in non-threatening, open-plan venues. They also used music to create a positive and relaxing setting.

Methods and approaches

Engagement actvities

User-centred activities

Poorly targeted activities can lead to apathy, discomfort, silence and conflict. Young people can find traditional approaches aimed at adults, such as surveys and interviews, boring and intimidating, while teenagers report feeling patronised by tasks designed for children (Nakarada-Kordic et al., 2017). To ensure rich outcomes for collaborative sessions, activities need to closely consider their target audience, adapting as the group learns more about the needs, abilities and skills of its stakeholders.

Visual, creative activities can allow children and young people to capture concepts and feelings they not be able to express verbally. Such activities include drawing (Morrow et. al), zine making (Batey, 2020), storyboarding, comic making (Rose and Björling, 2017) and assemblage (Orlowski et. al, 2018). One team used metaphors as 'linguistic artefacts', to help young people with schizophrenia to express and explore their experiences (Terp et al., 2016). One example they give is 'becoming a captain of your own life'.

Motivations and rewards

Participating in a research or resource development process can be time-consuming as well as emotionally and physically draining. To ensure sustained, enthusiastic participation, it is necessary to consider what drives young people to contribute and what they are taking away from the process. In one project, researchers used emojis to reward task completion and encouraged participants to take visual sketch notes during sessions to maintain engagement (Powell et al., 2021).

Researchers identified that co-design processes were in many cases intrinsically motivating. Young people valued being endorsed as experts, expressing themselves and being empowered to build resources that benefited them and members of their community (Nakadara-Kordic et al., 2017). It is also widely reported across design-led studies that the collaborative process can help young people to develop useful skills (Thorn et al., 2020) and learn about healthier habits (Scharoun et al., 2018).

Methods and approaches

Building resources

Making

Almost all design-led studies emphasise the importance of making for facilitating self-expression. Craft activities can empower young people to better express themselves, as well as enabling mental health professionals to think about their work in new and different ways (Orlowski et al., 2018) .

Continuous making and re-making is an approach that allows design and development to happen quite quickly. On average it takes 17 years for original research to be successfully integrated into practice (Hickie et al, 2019). By adopting an iterative making process, however, researchers included in this briefing were able to take the project from research to implementation much more quickly, in as little as 12 months.

Prototypes

Prototypes in mental health research are either created in collaborative processes or made for the group by designers or researchers. Prototypes are used to communicate and test ideas, explore the suitability of new resources, act as a starting point to collaborative processes and uncover insights.

Early in the design process, prototypes tend to be low-fidelity, paper-based or quickly drawn mock-ups to act as manifestations of thinking and early ideas (Sanders and Stappers, 2014), becoming more refined through continuous iteration. Digital prototyping has become increasingly common and allows users to make and visualise changes quickly (Johansson et. al, 2017; Terp et al., 2016).

Methods and approaches

Getting ready to deliver

Testing, evaluating

If a project intends to develop relatable, feasible and appropriate resources, a key part of the process involves gathering evidence from stakeholders about how well the product or service fulfils the needs of the group. Testing with users can also provide evidence of a project's success for funders or providers.

Evaluation is an important part of prototyping. One research team was able to provide early evidence of the success of their app due to high user satisfaction feedback from prototype testing (Peters et al., 2017). Another tested their activity book for children with ADHD over Zoom-based workshops, incorporating feedback directly into the next version of the activity book Powell et al. (2021). The group attributed the easy implementation of the activity book in healthcare settings, charities and schools to this user-led iterative process.

The best evidence is gathered when the prototypes are tested by the user group and in contexts where they would likely be used. For example, a series of games exploring the concept of resilience was tested with a group of young people with complex needs (the intended user) in schools (the primary context) (Hart et al., 2020).

It is also important to consider how to gather accurate data from users. Methods include feedback interviews with open questions (Powell et al, 2021) and user-led focus groups (Ruggiero et al, 2015). In one project, children were asked to make a drawing about their experiences of interacting with prototypes (Morrow et al., 2018). Researchers noted that drawing was better able than traditional evaluative methods to capture children's feelings and thoughts about the device proposal.

Key points

What lessons can design contribute to mental health research for children and young people?

Stay open-minded

Open research questions, allow for change, use creative techniques such as drawing and storyboarding to approach familiar challenges from new perspectives.

Prioritise collaboration

One of the key roles of the designer is to facilitate a collaborative environment. to esure that everyone feels safe and comfortable, and that their input is valued.

Consider young-person and child-friendly approaches

Capture lived experience and context of use in creating and testing resources. Working with the same groups over time helps to build trust, and therefore engagement as a group can define and learns from its experiments.

Engage through making and co-design

Drawing and sketching can help young people visualise their feelings and co-design can be empowering and build skills. Prototypes of early solutions can be tested and refined as ideas develop.

Let the users decide what works

Feedback and evaluation is built in to the design process, rather than an end product. Pay attention to how you gather data and how you can listen most effectively to the user on their own terms and in their own language.

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Appendix

This briefing has identified design research projects that support children's and young people's mental health. These papers were used to build the methods and approaches presented.

A summary of these resources is available here