MEANINGFULLY INVOLVING YOUNG PEOPLE IN MENTAL HEALTH RESEARCH
THE ROLE OF THIRD SECTOR ORGANISATIONS - POSITIVE EXPERIENCES AND CHALLENGES

YMCA DOWNSLINK GROUP

INTRODUCTION

This report relates to a programme of work completed by YMCA DownsLink Group (YMCA-DLG), entitled "A Pan-Sussex Youth Research Partnership: Young People's Experiences of the Impact of Mental Health and Well-being".

YMCA-DLG recognises young people as experts by virtue of their own experiences and aims to provide opportunities for them to effect change in the mental health sector. This change could be at an individual level, regarding their own treatment and support, or at a larger systems-wide level, where young people are able to influence decision-makers and leaders.

In recognition of young people having different interests and levels of ability, this Youth Research Partnership sought to provide a range of methods to enable young people to share their views, including opportunities to co-produce research in the area of mental health and well-being.

In the first part of the report we share some of our experiences of the Youth Research Project - the positives, practical issues and challenges, and ideas about how these might be addressed in future projects. In the second part of the report we outline the rationale for funding co-produced research in third sector organisations and aim to present a case for considering organisations such as ours as appropriate recipients of research funding. We hope that it will be helpful to other research teams, especially those based in third sector organisations.

The project was funded by NIHR ARC KSS, which aims to support young people to engage in health and care research (NIHR ARC KSS, 2023).

PART 1: A PAN-SUSSEX YOUTH RESEARCH PARTNERSHIP

Implementing the research

Establishing the YMCA-DLG project team and project boards
Establishing the Youth Research Partnership started with a core team of staff from YMCA-DLG (referred to for clarity from now on as the "YMCA-DLG project team"), this team are experts in Youth Participation and Youth Voice but none of whom had a professional background in research. A project board/steering group was established to agree and monitor the project plan, advise about research methods and ethical issues, track progress against milestones, and manage any risks or other issues arising. Members included the YMCA-DLG project team, a KSS representative, two researchers and a Brighton Youth Council representative. The original plan was to also include two youth representatives, but they reported feeling isolated in the group as discussions could include jargon. They therefore formed a separate youth project board, which ran alongside the main project board. A member of the YMCA-DLG project team met with youth researchers on a weekly basis to hear feedback and feed ideas and decisions from the youth project board back into the original project board.

Working with external collaborators
Four main external collaborators with knowledge of research methods and experience of conducting research with young people offered their support with the development and completion of the project. In addition to two of these collaborators sitting on the project board, they advised about research

methods and ethical considerations, contributed to research training for youth researchers, attended routine research meetings, responded to the specific questions and needs of the researchers, and helped the researchers to form links with other organisations involved in co-producing research.

Recruitment of youth researchers

12 youth researchers were recruited based on their interest in mental health and being part of a research team. Adverts were created by YMCA-DLG e-wellbeing Youth Ambassadors[1], and used to recruit people from two different groups: (1) 18-25 year-olds from universities in Brighton and Hove, and (2) 13-18 year-olds from existing YMCA-DLG Youth Ambassador and Mental Health Champions[2] groups. In total, 87 applications were received. Those who expressed an interest via the university route were asked to create a short video or write a brief paragraph explaining why they would like to be involved. Members of the YMCA-DLG project team reviewed all applications and initially selected 14 youth researchers (7 from each age group) based on their level of enthusiasm and interest in mental health. Two young people were unable to complete the project, leaving a final group of 12 youth researchers (for more details see below). Youth researchers were offered a £150 voucher for signing up, and travel expenses were paid. They also requested support with adding the experience to their CVs, and presenting findings to internal stakeholders.

Characteristics of youth researchers (self-defined)

Age (years)	2x 13y, 1x 17y, 4x 19y, 2x 21y, 2x 23y, 1x 25y
Gender	10x female, 1x non-binary, 1x not stated
Race	8x White British, 1x Japanese, 1x Persian, 1x White and Asian, 1x prefer not to say
Neurodiversity	3x neurodivergent
Disability	1x learning disability, 1x long-standing illness, 2x prefer not to say
Mental health	3x mental health condition(s)
Young carer	1x young carer

Training and support for youth researchers

All young people who volunteer with YMCA-DLG complete an induction as standard, to make it clear what is and is not expected of them, clarify how they can raise concerns, and detail how their information is used. Standard training includes: volunteer induction training, safeguarding, health and safety, diversity and inclusion, information and security, and professional boundaries. Young volunteers have a named, dedicated member of staff who they are able to raise concerns with, and who is available to check in regularly with them about their welfare.

In addition to the standard induction, specific training was developed to enable youth researchers to meaningfully engage with research activities. This took the form of an eight-session research training course, co-created by the YMCA-DLG project team and external collaborators, with input from the youth researchers about their needs. Sessions included: picking a research question, research methods and how to choose the best one for your project, literature reviews and critical appraisal, ethics in research, interview techniques and data analysis. Prior to undertaking the research, youth researchers were asked how they wanted to be supported. Their suggestions included having a calm room for anyone who

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1 E-wellbeing Youth Ambassadors are a group of creative 13-25 year-olds, who are passionate about improving emotional health and well-being for all. They are recruited through schools, colleges, universities and digital campaigns. They work with YMCA-DLG on campaigns and consultations, and give their views to the YMCA and other organisations. Group members have experience of undertaking research projects and delivering conference presentations and training. They meet every fortnight, allowing a regular space for project planning and involvement in research. The Youth Ambassadors programme has an open-ended recruitment cycle with new Ambassadors joining throughout the year.

2 YMCA-DLG has been funded to deliver a Mental Health Champions programme in schools in Brighton and Hove. This is a social action project to improve young people's mental health in schools. Recent activity has involved conducting peer-led research into young people's experiences in school, and making recommendations to head teachers. Through this programme, YMCA-DLG works with more than 100 students each year.

needed time away from the research environment, regular check-ins with YMCA-DLG project team members, and reflective practice groups. These were all incorporated into the research process.

Development and completion of research projects
The primary focus of the research process was to empower young people to take the lead. Two pilot projects were conceived, designed and conducted by the youth researchers, with the support of the YMCA-DLG project team. Both projects focused on mental health and well-being, with one exploring belonging and loneliness in schools, and the other focusing on experiences of and barriers to mental health care. The details of the projects are not going to be reported here, as the focus of this document is our experience of co-production, rather than the findings of the research itself. For more details of the projects, please see the e-wellbeing website (e-wellbeing Youth Research Projects - e-wellbeing).

Ethical issues and safeguarding
Following careful consideration by the project board, external ethical review was not deemed necessary. Ethical issues relating to participants in the research projects were identified and addressed, but will not be reported here due to the focus of this report. Ethical and potential safeguarding issues relating to young people acting as researchers, and steps taken to address these, are briefly outlined below.

Issue	Steps
Safeguarding	All YMCA-DLG staff are trained in safeguarding children and young people. Robust safeguarding policies, procedures and pathways are in place throughout the organisation.
Psychological well-being	A trauma-informed approach was used. Experiences and needs of youth researchers were considered in order to prevent harm. Support for the YMCA-DLG project team was provided by clinical leads.
Upsetting topics in research	Youth researchers were provided with safeguarding training. Regular well-being checks were completed. Research interviews were conducted in pairs with adult support. Reflective practice space was provided.
Disclosures during interviews	Training and adult support were provided.
Safety/accessibility of research locations	Risk assessments/management plans were completed.
Informed consent	Youth researchers were provided with adequate information to allow them to give informed consent to taking part. Information was provided about available support.
Accessibility of research interviews	Necessary adjustments were identified and implemented prior to research starting.
Bias	Training was provided.
GDPR and confidentiality	Training was provided and processes were checked by the YMCA-DLG GDPR department.

Evaluation and dissemination of findings
Youth researchers were asked for their feedback on participating in the research process. Below we will outline some of the main strengths and limitations of the project. For details of project outputs, please see the e-wellbeing website (e-wellbeing Youth Research Projects - e-wellbeing).

Experience of the project work and lessons learned

Initial planning
One of the main issues at the project-planning stage was some uncertainty about the level of research that was expected. The available resources (in terms of time and funding) did not make it feasible to deliver research projects of the quality that would be likely to be accepted for publication in peer-reviewed journals, and the generalisability of findings was limited by the scope of the projects. Our main priorities were that young people be enabled to take the lead in choosing topics for research to ensure these were in line with their interests, to provide opportunities for learning about research methods, and to facilitate active participation in all stages of the research process. Meeting these aims took time and we faced delays due to competing pressures on the youth researchers' time and energy (e.g. academic

work, paid employment, family circumstances), so there was inevitably an impact on the research that could realistically be completed. We felt concerned that there could be a mismatch between the project we were able to undertake, and the feedback requested by funders. While we believe that it is possible to co-produce research of the highest standard in third sector organisations, clarity about what is expected from specific projects in terms of quality and outcomes is essential, and needs to be adequately matched with appropriate funding and timescales.

Another issue we faced early on was some uncertainty about whether external ethical review was necessary. This was resolved but ongoing discussions resulted in some delays to the project timetable. Ethical approval processes are undoubtably an area where academic institutions are likely to have more experience and specialist support services, while third sector organisations are potentially going to find the prospect of completing external ethical review more daunting, despite their familiarity with ethical issues such as confidentiality, safeguarding and data protection. This is something that can be overcome with appropriate support, but should be considered early and factored into timescales.

Project team, project board and external collaborators
The YMCA-DLG e-wellbeing team are trained professionals who are expert in Youth Voice and Engagement, and have close links with young people in their community. The project board provided research expertise, oversight and advice. Inclusion of experienced researchers and a representative from the funding body helped to clarify necessary steps in the research process and highlight issues that required attention.

We benefitted from the support from a number of dedicated external collaborators, the vast majority of which was provided on a voluntary basis, and relied on donation of time, effort and expertise due to personal interest and investment in the project. This was hugely appreciated, but we do not believe it is a sustainable model for future work, as it leaves projects vulnerable to losing necessary support if experts are not willing or able to help without being adequately resourced to do so. It can also introduce barriers to asking for additional help when needed, out of a desire to not burden those who are offering support on top of their usual workload.

Strong collaboration between academic institutions and third sector organisations that work closely with young people is likely to result in the highest quality research focused on the priorities and needs of young people, taking the practicalities of co-production into account, and avoiding tokenistic involvement. Our experiences during this project highlighted that working relationships between third sector and academic organisations need to have a commitment to inclusion and meaningful youth involvement at their core, and be founded on mutual respect. From our perspective, technical language and differences in knowledge and experience can make academic research feel daunting and inaccessible, and there have been occasions where our experience, knowledge and skills have felt undervalued.

Youth researchers
We were successful in recruiting an enthusiastic group of youth researchers, who showed a high level of interest in and dedication to the project. The group contained young people aged 13 to 25 years, with a range of mental and physical health conditions and neurodiversity. The group was almost entirely female and the majority described themselves as White British, suggesting work needs to be done to increase inclusiveness and accessibility in terms of gender and ethnicity.

All youth researchers were supported by a named member of the YMCA-DLG project team, which allowed the development of strong relationships and creation of safe spaces for young people. They were able to participate in research training, not only as trainees but also in terms of shaping the content of the course according to their needs. They were supported to make key decisions about the project from beginning to end, setting the agenda for research topics, identifying target populations, choosing methods and suggesting desired outcomes. Throughout the project there was a strong focus on

accessibility, opportunities for learning and leadership, and the well-being and safety of youth researchers. Examples include a flexible model for online or in-person meetings, provision of confidential spaces for debriefing, and clear bidirectional expectations between youth researchers and the YMCA-DLG project group. Feedback was welcomed and acted upon as quickly as possible – for example, making changes to the project board as outlined above.

Ensuring that youth researchers are able to retain decision-making power and translate their ideas into high quality research requires thought and effort, given their relative inexperience with the formal research process. We believe that this effort is worthwhile, and that good outcomes in co-produced research are possible, so long as expectations are clear from the outset and adequate research supervision is available. The model of co-production also needs to be carefully considered and agreed before research projects begin. For example, it is useful to consider the pros and cons of adult researchers taking more of a background supportive role versus being equal members of the day-to-day research team.

Finally, a general issue across youth participation projects (not exclusive to research) is how young people's involvement can be tokenistic and exploitative, rather than meaningfully inclusive and adequate in terms of reimbursing young people for their time and effort. Future projects need to consider the ethical considerations around some members of the research team (adults) being paid for their time and others (young people) not being paid. There may be legitimate reasons why payment is problematic (for example, having a negative impact on benefits or being seen as inappropriate by parents or carers), but these need to be explicitly considered and reasons for final decisions about financial compensation need to be transparent and open to scrutiny.

Youth researcher feedback

Below is some of the feedback provided by youth researchers. This has not been subject to any formal analysis, but the quotes chosen exemplify some of the main points that were made.

Positive feedback

"[I enjoyed] sharing ideas, working on a current topic for research and working with researchers."

"[I enjoyed] learning the processes of conducting research, collaborating with my peers on something I'm passionate about, the friendly environment of our meetings."

"I have enjoyed the group discussions and the way they feel safe and confidential."

"I enjoy being free to share opinions and making strategies around collecting data, the team is really respectful and makes the experience not only enjoyable but memorable."

"I think we work pretty well together, it is never quiet and everyone is given a chance if they wish to share their ideas."

"I like how the discussions have been held and how there was no pressure in getting involved in these discussions. Working as a team was a great treat for me."

"It was a beauteous experience to get to know people of a range of backgrounds and ages, which managed to improve my socialising skills and make me comfortable in speaking in front of others."

"I was happy to be taught important research skills by professionals."

"It was great to get involved, the topic was fun to work on and it also gave me a greater sense of community [in the local area]."

All respondents (N=7) responded affirmatively to the following:
- That they had an equal say making decisions during the project
- That they felt safe during research sessions
- That they enjoyed taking part in the project
- That their time and contributions were recognised fairly
- That research sessions helped increase their understanding of research projects

Skills that were identified by the youth researchers as having developed as a result of involvement in the project were: teamwork/collaborative skills, research skills and knowledge about research processes, logical thinking, building on others' ideas, communication skills, time management, interview skills and flexible thinking.

Suggestions for improvement

Suggestions for improving the experience of youth researchers included:
- More clarity about who is responsible for completing tasks, timescales, and discussion about how tasks should be carried out
- Tighter time management in research sessions, leading to greater productivity (although it was acknowledged that it was also helpful to have time to chat and get to know others informally)
- Holding sessions in-person rather than online, to improve the chances of people attending
- Setting more between-session tasks to enable work to continue even in the absence of meetings
- More frequent research meetings, planned further in advance to facilitate diary management
- Making sure everything from previous meetings was recapped at the start of research sessions
- More opportunities to put learning about research skills into practice

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PART 2: THE RATIONALE FOR CO-PRODUCTION OF RESEARCH

Co-producing mental health research with young people

Co-produced research (also referred to as co-inquiry, community research, participatory research and peer research) is research resulting from collaboration between researchers, practitioners and members of the public, during which responsibility and power is shared (NIHR ARC West, 2024). The aim of involving members of the public is to ensure that research is carried out in partnership with the people it is most likely to affect, rather than being done on their behalf (NHS Research Authority, 2020). An important element of co-production is inclusiveness, meaning that attention should be paid to those who are frequently overlooked in the research process, and efforts made to give a voice to those who are seldom-heard (Wellcome, 2020).

The imperative to include young people in research that affects them forms part of the United Nations Convention on the Rights of the Child, and mental health challenges have been identified as one of the issues disproportionately affecting this age group (Wellcome, 2020). Involving young people in a meaningful way should produce mental health research that has a higher chance of being more relevant, ethically acceptable and understandable to participants, and provide them with a better experience of taking part (NHS Research Authority, 2020). It has been argued that co-production with young people has a positive impact not only on the research itself, but also on those who participate and the communities to which they belong (Wellcome, 2020).

Despite these potential benefits, young people are often excluded from the research process. This may be down to concerns about the safeguarding or competence of young people (Wellcome, 2020), additional resources that can be required for effective co-production, or the potential negative impact of co-production on research quality (Kelly et al., 2017), and/or existing professional hierarchies and societal inequalities (NIHR ARC West, 2024).

The role of different organisations in research

Most research, including co-produced research, is currently based in academic research departments. This is understandable given the expertise found in academic institutions and support structures in place to assist with education and training, adherence to relevant laws and regulations, and ensuring high-quality research. Much of the advice published for those undertaking co-produced research therefore appears to be aimed at academic audiences, including advice around how to engage and maintain strong relationships with relevant researchers from the population of interest and organisations that support them.

Why third sector organisations can be well-placed to do mental health research with young people[3]

In many parts of the UK, third sector organisations provide a significant proportion of mental health and well-being services for young people, meaning they have relationships with those who are likely to have an interest in and relevant experiences to contribute to mental health research. For example, approximately 70% of the young people who work with YMCA-DLG access support for their mental health. In Sussex and Surrey, YMCA-DLG provides community and school-based counselling services, and services in the areas of accommodation and tenancy-related support, homelessness-prevention and family mediation, universal information, advice and guidance, and sexual exploitation and harmful sexual behaviours.

Third sector organisations also frequently work with young people who belong to groups seldom heard from in research. For example, YMCA-DLG provides support for care leavers, young people from diverse ethnic and cultural backgrounds, unaccompanied young people who are seeking asylum in the UK, young people with physical disabilities and/or learning disabilities, LGBTQIA+ young people and young people with mental health needs.

As well as developing strong relationships directly with young people, third sector organisations are often part of local networks of services who support them, facilitating research recruitment and collaboration between key stakeholders, and providing opportunities to quickly translate research findings into practical actions. For example, YMCA-DLG has relationships with a range of Local Authorities and health, voluntary and community sector organisations, many of which have established participatory groups who can be invited to join research opportunities. Through direct provision of services and relationships with other providers, third sector organisations are often acutely aware of pressures faced by the systems around young people, and the need to develop creative solutions to overcome some of the challenges of providing quality support.

The ethos of third sector organisations who work with young people should be very much aligned with the ethos of co-produced research – that is, a commitment to centring the priorities and needs of young people and providing support to enable them to participate in research in a meaningful way, avoiding tokenism. For example, as an organisation, YMCA-DLG is committed to sharing power with young people, giving them the opportunity to deliver against the things that are important to them.

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[3] In this section, we have used YMCA-DLG to exemplify the points made, but we would like to acknowledge that there are a number of other local third sector organisations who are well-placed to undertake co-produced research, and in some cases are already doing so (for example, Trust for Developing Communities: https://trustdevcom.org.uk/research).

Finally, third sector organisations working with young people should have experience of prioritising accessibility and safety. For example, YMCA-DLG understands the importance of flexibility and has experience of using a range of tools and techniques to make sure it delivers individualised and accessible support to young people with a range of needs. YMCA-DLG has translation services, specialist staff, and a diverse and inclusive workforce with access to ongoing CPD and learning opportunities. YMCA-DLG is committed to working with young people in a trauma-informed way, and to creating psychologically safe environments. Robust safeguarding procedures are in place, and training and support are provided to youth volunteers.

CONCLUSION

We firmly believe that third sector organisations can make a positive contribution to the field of co-produced research, and that they should be considered as potential funding recipients. However, where there is a lack of formal research training and expertise in these settings, this can pose a challenge to the production of high quality research, and adequate funding is required to ensure that internal expertise can be acquired, or external collaborators can be compensated for their time. The enthusiasm and dedication of our youth researchers was resoundingly clear throughout this project, showing that young people want to be involved in research, to add to its value and quality, and use it to make meaningful change. We believe that with the right training and support, and if the potential challenges of co-production are adequately considered and addressed, including experts by experience in research teams can lead to research that finds new, insightful and inspiring ways to bring about positive change.

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