Citizen Science and Youth Mental Health: Co-creating Future Research

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Youth LIVES (LIVed experience of Evidence Synthesis) is a UKRI-funded Citizen Science Collaboration award. The project aims to bring together young people with lived experience of mental health problems with researchers, to work together to discover evidence gaps and to co-create research proposals that meet the needs and priorities of young people themselves.
Our approach

Using interdisciplinary approaches to enable youth citizen scientists to design and develop research from the beginning of the process in collaboration with established researchers.

- Co-creation
- Patient and Public Involvement (PPI)
- Citizen science principles
- Evidence synthesis
“Citizen science” as a term has increased in popularity over recent decades, but volunteers have long been involved in collecting scientific data. Involves non-scientists collecting data, but can also get involved in other stages of the scientific process too - co-created citizen science is where volunteers get involved in ALL stages, from designing research questions through to dissemination. Contributory citizen science projects are those which volunteers just collect data, UK examples are Big Garden Birdwatch, Big Butterfly Count. Most citizen science projects in the UK and US focus on biodiversity, other popular fields are astronomy, air quality monitoring, with fewer in the social sciences or health. Our project was one of the first to be funded in Mental Health.

PPI(E) overlaps with Citizen Science in various ways, but there are differences. Citizen Science expects the input from the public to directly contribute to research and data, whereas PPI (E) can often be more advisory (not always!)
Theory of Change

Youth attend Q&A sessions → Youth gain confidence in talking about science
Youth and researchers take part in Teams → Enhanced skills and knowledge in researchers
Workshops/seminars about Youth LIVES process → More people using Citizen Science approaches in Mental Health research

New outputs for dissemination → New primary research on mental health
New evidence syntheses → More relevant, accessible and impactful mental health research
Enhanced skills and knowledge in youth
Case study 3: Youth LIVES

Timeline

Phase One 2021 - 2022
- Q&A sessions for youth citizen scientists on Discord with mental health researchers
- Reflection and evaluation sessions
- Workshop on research methods
- Ethics
- Safeguarding

Phase Two 2023 - 2024
- Citizen scientist/researcher team meetings (monthly)
- Q&A sessions
- Journal club for researchers
- Co create proposals
- Safeguarding

Extension 2024
- Co created proposals to be shared with community groups, other MH organisations, and researchers
- Celebration event with policy and charity stakeholders
- Co-created evaluation sessions
- Dissemination of academic findings
## Research teams

<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
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<tbody>
<tr>
<td>Access to mental health support &amp; Mental Health support in schools</td>
<td>Cultural barriers to accessing mental health services in schools and interventions to overcome them</td>
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<tr>
<td>Neurodiversity and Mental Health in young people</td>
<td>The mental health and support of young people waiting on a neurodiversity diagnosis</td>
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<tr>
<td>Suicide and self harm in young people</td>
<td>The effects of interventions for young people at risk of suicide and self-harm on coping styles and help-seeking behaviour</td>
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<tr>
<td>Mental Health and pets and animal companions in young people</td>
<td>The impact of pet ownership and pet therapy on the mental health of young people and the pets</td>
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Challenges & opportunities

**What’s worked?**

- **Partner support**
  Leaders Unlocked for recruitment, advice, safeguarding

- **Q&As**
  As capacity building activity

- **Timelines**
  Taking time to create research questions

- **Funder activities**
  Networking and advice from other projects

- **Use of technology**
  Discord, Zoom, Whatsapp, Jamboard

- **jamboard workbook**
  To facilitate and workshop thoughts and ideas

- **Youth engagement**
  Interest and excitement in the project and method
Challenges & opportunities

What’s been difficult?

Scheduling
Finding time to be inclusive of all

Power dynamics
Researchers understanding their role as co-creators

Safeguarding
Lack of support in reporting

Resourcing
Time and support on the project (and funding decisions)

Ethics
Balancing institutional ethics and citizen science principles

Decisions
Such as deciding on a research question - many interests!

Institutional support
Lack of understanding/systems = difficulties across payment, safeguarding, and ethics
Challenges & opportunities

Scheduling
- Being more selective when forming groups to try and match lifestyles

Resourcing
- Cost in a project manager, as well as partner support for throughout the project

Decisions
- Find meaningful ways to come to decisions, not just surveys

Power dynamics
- Set expectations at the start - be explicit!

Safeguarding
- Check institutional support/guidance from partners before project start - can you do this project safely?

Institutional support
- Network early! Find out where there may be support internal and external. Disseminate.

Ethics
- Create a separate ethics document that relates to principles of CS - try to embed this into institutional ethics where possible (e.g. cover letter)
Thanks for listening!

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