Including children and young people in research in start-ups

A Zinc Contribution to the 2021 Engage Unconference

Who are we and why do we care about this?

Zinc aspires to be the most trusted place for entrepreneurs, innovators and researchers to experiment their way to impact at scale in our chosen missions to: improve mental health; enhance the quality of later life; ensure that the future of work is good for both employers and workers; and help people reduce their negative impacts on the environment. In our flagship venture-builder programme we bring together cohorts of ~70 talented individuals from a wide range of backgrounds in a 6-12-month, full-time programme. We help them find co-founders and develop and build highly scalable businesses to develop brand new products and services from scratch. Each venture-builder hones in on an aspect of one of our four broad mission areas. Previous programmes have focused on women's mental health; the future of work in places 'left behind' by automation and globalisation; and adding quality years of life to old age. The businesses created within a venture-builder must respond to its particular mission area and the products and services they develop must be intended to deliver positive impacts at scale for relevant communities.

The venture-builder is anchored around a robust approach to research and development, including both in-house R&D support and mutually beneficial partnerships with researchers in and beyond universities. User engagement, collaboration and co-production are also central to our approach to venture-building. We believe that the sorts of science-rich start-ups we help build are able to both create and leverage important opportunities for a different type of public engagement with research. This relates particularly to the 'applied' research carried out in and by start-ups themselves, often with support and input from academic colleagues. Engaging with and collaborating in research in start-ups gives participants a meaningful voice in the development of new products and services which may one day deliver impacts at scale in areas that matter to them.

Involving the intended end users of those products and services is perhaps nowhere more important – or more potentially challenging – than in the context of our current mission to improve the emotional and mental wellbeing of children and young people. Not only is it important to respect the rights of children and young people (CYP) to have their voice heard in this context, it's also essential to making the change that we want to see. To create solutions that are effective and desirable, our Founders will need to develop a deep understanding of the experiences of children and young people, and innovate based on their genuine needs, desires, problems and interests. They also need to make sure that the young people who work with them

enjoy an experience of research engagement that is at least as rewarding and valuable to them as it is to the Founders working with them.

On 1 November 2021, 68 new Founders joined us, all keen to deliver change in key areas relevant to the mental health of young people. We will do whatever we can to help them involve children and young people at every stage of product development, from understanding problems and developing ideas for solutions through to testing concepts and prototypes. We'll also encourage Founders to move from consultation (hearing people's views) towards true co-design and collaboration (working together and sharing the power to make decisions). Importantly, we hope to develop new modes and models of working with CYP that ensure genuinely mutual benefit to all participants.

What's this document for?

In preparation for our new venture-builder we have done quite a lot of research, including talking to experts within and beyond academia, about why it's important to include CYP in the process of developing products and services for them and how we might go about doing that. The rest of this document summarises key findings from that research and provides advice to facilitate the productive and responsible involvement of children and young people in research in start-ups. We have written this primarily for an audience of new venture-builder Founders and parts of it will likely be too introductory for public engagement professionals. However, we hope some of it will also be of interest to the Engage Unconference community in thinking about their own engagement with CYP.

Through the Unconference, we shared our first draft of this document with a wide range of public engagement professionals and others with experience of working with CYP. What follows is based on our own research but now also reflects and incorporates feedback and input from that community of experts. We're really grateful to everyone who has commented on and added to this document. We're also still keen to hear your thoughts and learn from your experiences. If you have insights or ideas that you'd like to share, just send an email to rachelm@zinc.vc to tell us what you think or to set up a call to talk about this more.

A note on safeguarding: We have included some information here about safety and safeguarding but this document is not intended to provide comprehensive guidance on these essential issues. We are interested here in exploring exciting, effective and rewarding ways to work with CYP, recognising that any such engagement can only happen once appropriate safeguarding measures have been put in place and continue to be upheld.

What we've learned so far

Involving children and young people in research in start-ups - particularly as it relates to product or service development - can unlock huge amounts of creativity and generate important insights, but making the most of these opportunities requires expertise and a carefully thought-through approach. Here are five key things we've learned.

- After a year of disruption, many young people feel marginalised or ignored and would value the opportunity to have their voice heard and contribute to positive action to improve mental health.
- Understanding some key aspects of how children develop as they get older can help to plan involvement activities that are appropriate for the age of the children or young people you work with.
- User research doesn't just mean questionnaires, interviews or focus groups, though these might be useful in some circumstances. There's a wide range of techniques you can use to get deeper insights, with different techniques becoming relevant at each stage of product development.
- It's especially important to be transparent and authentic. Children and young people are
 likely to see through a facade but you can earn their respect by showing your passion for
 the issues under discussion, listening deeply and actively, and backing up your words
 with actions to make a difference.
- Recruitment is likely to be the hardest part of involving children and young people. It is
 never too early to start building relationships with organisations you could partner with to
 hear the views of young people.

Why should founders involve young people?

- Participation is often the most existing, fun and rewarding part of CYP mental health and it's where the real transformation comes from.
- Involving children and young people will help you to create products and services that successfully tackle real pain points
 - To build something that is desirable and will be used, you need to understand the genuine needs, wants, contexts, routines and behaviours of the people that you're designing for.
 - The more insight you have into your users, the better you'll be able to create a
 product that people will want and be willing to pay for.

- Whether your customers are young people, parents or public services, involving young people in the design process will help you address a real need - and help you to demonstrate that you're putting young people at the heart of your venture.
- The physical and digital world that children and young people inhabit has changed drastically in the last 5-10 years. Hearing from young people can help us avoid reliance on our own biases which may be inaccurate and out of date.

This guide will help Founders maximise the value of time with users

- By carefully planning the way you involve users and moving beyond defaulting to standard questionnaires, interviews or focus groups, you can maximise the value of the insights that you gain and avoid certain biases that can mask the true picture.
- The advice in this guide will help to:
 - Reduce the impact of social desirability, so people are less likely to be swayed by their impression of what you want to hear.
 - Get closer to understanding people's actual behaviour which is often different from what they say in a survey.
 - Ask the right questions and reduce the extent to which your own preconceptions influence how you interpret the answers.

When to involve users in product development

Children and young people are just one of the stakeholder groups that it may be important for you to involve in product development. This guide includes some discussion of them, too, because there are additional considerations to take into account in involving parents, carers or relevant professionals.

Always take opportunities to hear people's views

- This guide will help to develop planned activities to gain insights, but it's also important throughout product development to seek out and take up informal opportunities to hear people's views.
- Be proactive in talking with the people around you and get their thoughts on what you're working on, but be careful not to be intrusive. You might consider using conversations with family, friends, people you meet on the street to collect opinions and gain different perspectives. Every conversation you have can help shed new light on the problem you're tackling.

Informal conversations might help you think of hypotheses to test, consider the
assumptions you're making, or lead to opportunities to involve someone in more
formal activities (recruiting people is one of the hardest parts of user
involvement).

• Consider involvement at every stage of product development

 The way you engage people may be different depending on which stage of the cycle of product development you are at. Examples of involvement at different stages include:

Define: Identifying and defining the problem

■ Learning from existing research and accounts of experiences, explorative interviews or workshops to understand areas of importance

Understand: Building an in-depth understanding of the problem

 Interviews, questionnaires, visits and immersion in relevant settings, workshops

Ideate: Develop ideas for solutions

■ Idea development workshops, selection of ideas/concepts

Experiment: Prototype and test

- Testing engagement, efficacy, usability
- User involvement at each stage avoids wasting time on building something that people won't want to use.

Principles for successful involvement of children and young people

Move from consultation to collaboration and co-design

- In consultation people's views are heard, but power and decision making remains with the designers. In collaboration and co-design, people from outside the project team are given an equal status with the design members. Power is handed to members of the public involved in the project and they have a meaningful say in decisions.
 - This is a spectrum, and different levels of co-design may be appropriate at different stages. There are many ways to add co-design elements, for example:

- Training peer researchers to help design and carry out questionnaires and interviews.
- Running ideation workshops where the people you invite are empowered to develop ideas and vote on which concepts should be taken forwards.
- Involving people over a longer period rather than in a single activity, with an element of power given to them at each stage.
- Moving from consultation towards co-design allows greater influence for important stakeholders, who include people with lived experience (of mental health, but also more generally of being a young person today), as well as people with professional experience. This can help to reduce the influence of your own biases, allow you to tap in to users' knowledge and experience more deeply, and benefit from the creativity that can emerge from combining diverse viewpoints.

Engage responsibly

- Make sure anyone participating is fully informed and consents to take part.
 - It's essential to ensure that children and young people are fully informed about the purpose of the activity and what their involvement will be. It should be made clear that their participation is voluntary and they can withdraw at any time they like.
 - In addition to the child's own consent, you will need to obtain the permission of a responsible adult (i.e. parent, guardian or teacher) to include anyone aged under 16. Depending on the young person's particular circumstances, parental consent should also be considered for those aged 16 and older.
 - You should take a proportionate approach to how you inform people and get their consent. If you are hosting a conversation with a small group of 17 year-olds, sending an email in advance about what's involved may be enough information; if they then choose to join the session that may be sufficient consent. If you are involving 14 year-olds with anxiety in a test of your prototype over several weeks to see if it helps improve their wellbeing, it will be more appropriate to use a formal information sheet and collect a signed consent form. How formally you approach providing information and recording consent may depend on: how vulnerable the participants are (age, health, etc.); how intrusive the activity is and whether there's potential harm (asking questions about what products they buy vs asking about their experience of mental ill health); how intensive the activity is (is this a one-off session, or are you asking them

- to contribute regularly over a longer period); and to what extent your activity is a step away from the kind of activities they would generally do.
- If your research is more like an academic study, aiming to create generalisable findings (rather than simply develop your own product), or working with clinical populations and influencing their care, there may be formal requirements for ethical approval.
- NSPCC provides a <u>template consent form</u> for involving children and young people in activities. The Health Research Authority <u>provides</u> <u>templates</u> for involving children and young people in academic or medical research studies.
- Take responsibility for safeguarding children and young people's wellbeing
 - Everyone has a responsibility to promote the welfare of all children and young people, to keep them safe and to work in a way that protects them.
 - Children and young people should never experience abuse of any kind.
 - As you develop your venture, you will need to put appropriate safeguarding policies, procedures and a code of behaviour in place.

Make the process rewarding

- Having their voice heard and contributing to improved mental health is in itself something that children and young people are likely to value. After the disruption of COVID-19 many young people feel ignored.
 - Give feedback after involvement activities so that those involved can see what happened as a result of their input
- Consider remunerating CYP for their time. Not remunerating them can risk reducing diversity, particularly if you're working with young people over the age of 16 who cannot afford to give up their time for free when they have competing work and study commitments.
- While payment for time (e.g. in the form of age-appropriate vouchers) may be desirable, we understand that it is not always possible. Think creatively about how else you can offer value.
- Children and young people are likely to value the skills they gain through involvement, including greater confidence to share their voice.
 - Consider how you can design activities to enhance skills (the <u>Skills</u> Builder framework is useful).

- Offering something that will directly benefit children and young people may be a good way to start a relationship with individuals or organisations (e.g. sharing careers experience, mental health knowledge, entrepreneurial knowledge)
- Think about how you can give CYP something to show for their involvement. That may be badges or stickers for younger children, or a certificate of participation and experience that can go on the CV for those who are older.
- Try to build longer-term relationships this is more rewarding for participants and gives you the possibility to return when you need participants at later stages of your process.
- Remember to reduce barriers to engagement where possible, including by considering things like when (on which day, at what time of day, during school holidays or otherwise) as well as where and how you engage with CYP.

• Engage with underrepresented groups

- All young people should feel like they belong, regardless of their orientation, gender, ethnicity, abilities, background, etc. Encourage them to be their authentic selves. In all their interactions with you, young people should feel that they matter, that their ideas matter, and that they can make a difference.
- People who are underrepresented in product and service design and delivery often have the greatest needs. People may not feel empowered to take part, and greater effort may be needed to reach people who are typically underserved. It may help to work closely with charity and community partners who have already developed trusted relationships. Such groups might include young people from the following sorts of groups:
 - Low income families
 - LGBT
 - Black, Asian or minority ethnic
 - Young carers
 - Care experienced CYP
 - CYP with SEND
 - Unaccompanied asylum seekers
 - Religious froups where MH stigma is present.
- Young Minds have a toolkit relating to these issues.

• Create a safe space

- Children and young people may be nervous or unsure of your motives. They may also be very eager to give answers that please. In order to gather genuine insights it is important to create a safe space where young people feel they can share their views honestly.
- Adults have a tendency to selectively hear and interpret what young people say.
 It's important for adults to genuinely listen to understand what young people are trying to say.
- Create the right space and you'll get wonderful ideas. Different methods to facilitate and allow young people to express themselves may be helpful e.g. using interactive facilitation and getting people moving around the room, using flip-charts and sticky notes, bringing in drawing alongside talking and writing.
- Learning to work with children and young people takes time, and the needs of different age groups are very different. If you're working with schools or youth groups, get support and advice from them on how to make the most of opportunities.
- A lot of people don't know where to start when you're talking about mental health
 it can take time to unravel it all before you can delve into the areas you're most interested to understand.

Be as transparent and authentic as you can

- Show why you care about the issue(s) you're talking about and be clear about why you're involving young people.
- Be clear about what you're asking, what you will do with the information, and how much power young people will have. Whether what you're doing is closer to consultation or closer to involving young people as equal co-designers, make sure you are clear about how much of a say they will have and set expectations honestly and fairly.
- You will get direct questions and need to be able to answer them in a direct and simple way. You might find that young people want the solution tomorrow at the latest. Don't promise things you can't deliver.
- Be clear about the feedback they can expect to receive and the mechanisms via which they can expect to receive that feedback.

Planning

Define the purpose of your involvement activity

- Think about at what point of product development you currently are and what input you need; design activities to meet those needs.
- Whether you are exploring a problem, developing ideas, or testing a concept or product, it's important to clearly define your objectives for the activity. You may want to answer certain research questions, test assumptions, gain insights into aspects of people's lived experience or generate ideas for new products or features.

Choose your involvement methods

- Consider where you want to place yourself on the spectrum from consultation to co-design.
- Make your activities age appropriate and unlock deeper insights by moving beyond interviews / questionnaires / focus groups.
 - Consider the stage of cognitive development of the age group you plan to work with, and what activities they will be most able to engage with. As a simple guide: for ages 0-6, most value may be gained by involving parents; engage children aged 7-12 through play or offering simple choices; for those over 12 you may be able to ask more open questions.
 - Some user researchers consider 7-11 a particularly good range for prototyping with children: younger than this and they have difficulty expressing themselves verbally; older than this and more care is needed to ensure adults' and peers' expectations are not unduly influencing their responses.
- A table of techniques that can be used in co-design sessions (along with the developmental skills that children need to take part) is here.

Recruit people to take part

Recruitment is likely to be the hardest part of involving children and young people in your work. It's a useful first step to identify a person or organisation that is already known to and trusted by those who are harder to engage. These sorts of trusted people could include, for example, a religious leader if you're hoping to engage with faith groups, or a case worker if you want to engage with disadvantaged families. If these people are brought on board before you even start trying to approach your target groups, it's no longer a 'cold call' approach to engagement but a collaborative, partnership approach. The trust you build at the

- start of your project increases the accuracy and honesty of the information / insight gathered
- Succinctly explain what people who take part will be asked to do. For young people, make this an opportunity for them to have their voice heard and make your passion and the social purpose clear.
- For children aged under 16, you must get permission from a parent, guardian or other responsible adult (e.g. their teacher)
- Use your networks to find gatekeepers that can help you reach the people you want to involve: this may be teachers, youth workers, parents.
- Schools may be interested in the value involvement can offer, developing skills and meeting <u>Gatsby benchmarks</u> (encounters with employers and experiences of workplaces). They are likely to have planned out activities well in advance, but may have some flexibility to help find ways of involving pupils, especially if you have a connection to the school rather than getting in touch via cold outreach.
- The people involved are unlikely to be perfectly representative of the wider population, but aim to get a diverse a range of people involved as is relevant for your objectives (e.g. people from different geographical areas, socioeconomic status, ethnicity, religion, gender or sexual identity, disability)
- Reimburse the expenses of people who get involved. Consider what incentives you can offer (see 'Make the process rewarding' above).
- o Understand key dates in the school calendar and religious observances.

• Plan to keep people safe

- Key points what are your responsibilities?
 - Safe practices to recruit and select staff and volunteers. You must particularly ensure that barred individuals do not carry out regulated activities (DBS checks).
 - Safeguarding measures. Staff and volunteers should be aware of their responsibilities to recognise abuse and bullying. They should know how to respond to child protection concerns, including allegations against children and adults involved in your activities, and how to make a referral to a local authority or the police if necessary.
 - Collect appropriate details to allow a safeguarding referral to a local authority in case it is needed (i.e. name, date of birth, school or address)
 - Recording and storing information appropriately in compliance with GDPR
 - Appropriate health and safety to manage physical risks
 - Effective measures to prevent and respond to bullying

- Informed consent from all young people and children and additional parental consent for anyone aged under 16.
- Always have two adults in the room (even if virtual), one with appropriate DBS check
- Use a form of communication that is shared with at least one other adult (e.g. shared email inbox, shared mobile phone). Don't give your personal contact details or contact young people using your personal social media accounts.
- NSPCC recommends implementing safeguarding policies and procedures, and a code of behaviour.
- NSPCC also provides guidance on <u>recommended adult to children ratios</u>.
- Consider the risks of the activity you are carrying out and the environment in which it is happening. Take steps to mitigate risks and avoid harm.
- o If discussing mental health, design and frame the session in such a way that it is clear that this isn't therapy or an intervention, minimising the chance of being put in the situation where you are involved in any individual's care. However, you should also make sure that you identify any support requirements that might come up during the session and have thought about organisations or support to which you could direct people if need be. Come to your session prepared to deal with concerns appropriately and signpost people to further support if needed.
- Hearing about distressing experiences can take its toll on those who are carrying out research. Support your colleagues with time to discuss and process what you've heard, and reach out for support if you need to talk things through.

Resources

- Zinc's approach to user research animation: 1) deepening understanding of the problem 2) engaging with underrepresented groups 3) choosing the right research method(s) 4) make the process rewarding.
- Zinc's collection of insights into lived experiences
- Zinc's quide to conducting user research remotely includes list of tools that can be used
- <u>NSPCC on safeguarding</u> their resources for voluntary and community groups are also highly relevant to mission-led startups. Key aspects to develop are a nominated child protection lead, safeguarding policy and procedures, code of behaviour, safe recruitment of staff and volunteers, and a plan to keep up to date.
- Youth Centered Design toolkit from UNICEF Canada's One Youth movement. Runs through a specific co-design process in detail - from creating a safe space, building

- personas and defining an opportunity, through to generating ideas, building prototypes and getting feedback.
- <u>Toolkits from Young Minds</u>, including resources advising on involving vulnerable or marginalised children and young people in service development. Explores vulnerability and principles for engagement.
- The <u>Market Research Society code of conduct</u> has standards for conducting market research with children (under 16).
- Research recruiters Angelfish Fieldwork have <u>advice when recruiting for market</u> <u>research</u>. Find a gatekeeper, get consent, create a friendly environment, choose the right method, choose the right researcher or facilitator, choose incentives wisely.
- NIHR guidance for involving children and young people as advisors in research (comes from the perspective of health research in universities and health settings). Include: Tips, planning, recruitment.
- <u>UNICEF compendium on Ethical Research Involving Children</u>. A long and detailed document with an international lens. Useful sections include pg.33 7 principles for ethical research, pg 60 & 69 guidance on research and on consent
- <u>Co-designing with young people</u>, a guide from Orgyen (Australian National Centre of Excellence in Youth Mental Health).
- NHS Ladder of Engagement a useful tool in thinking about moving from informing or consulting to true collaboration (and indeed beyond).