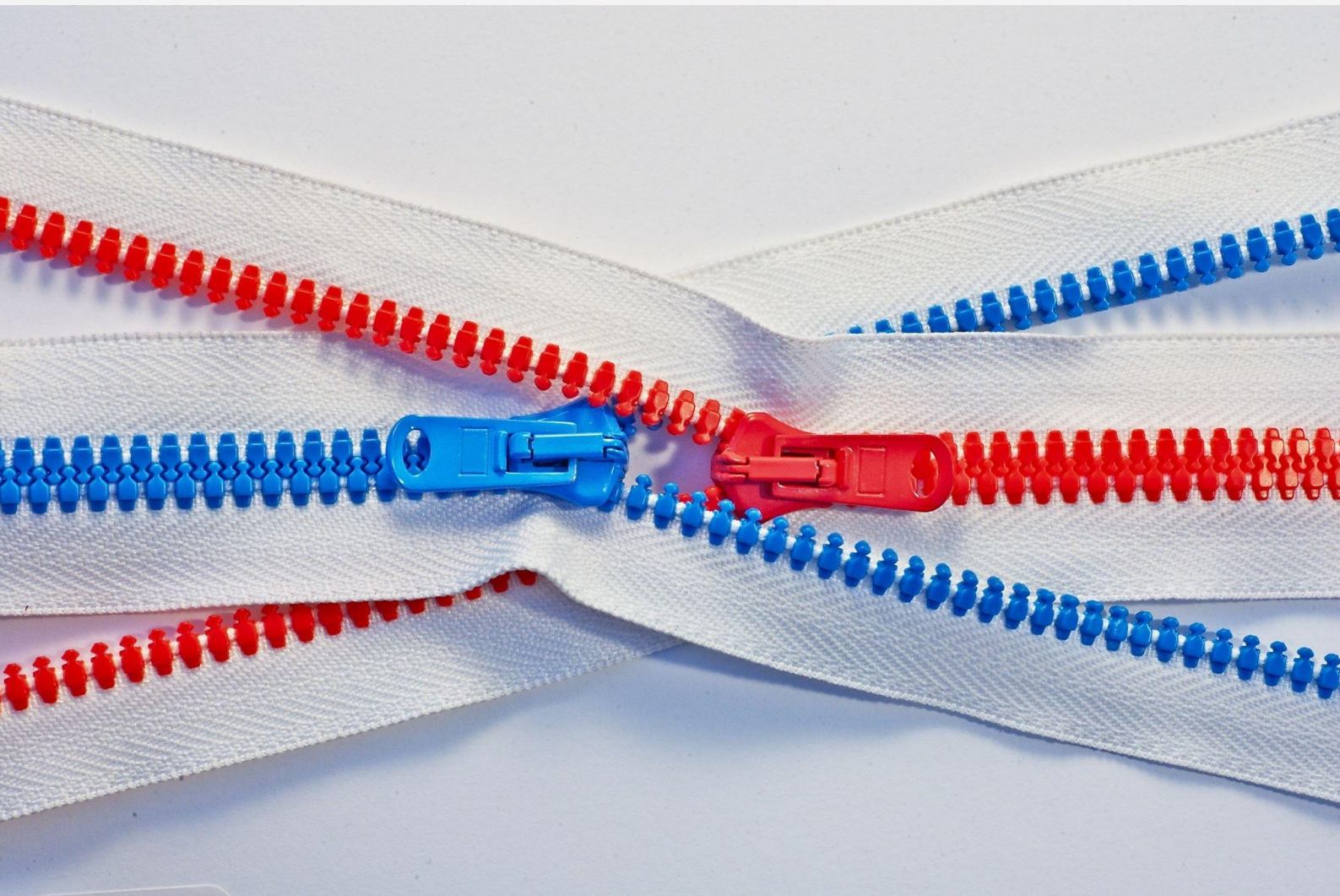


Tackling ‘Taboo’ Health Issues through Research and Development in Startups

Short report on learning from a Venture Research Programme, led by Zinc and funded by the Wellcome Trust



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NOTE: This report discusses sensitive health topics, including pregnancy loss and suicide, that some may find distressing.

Introduction:

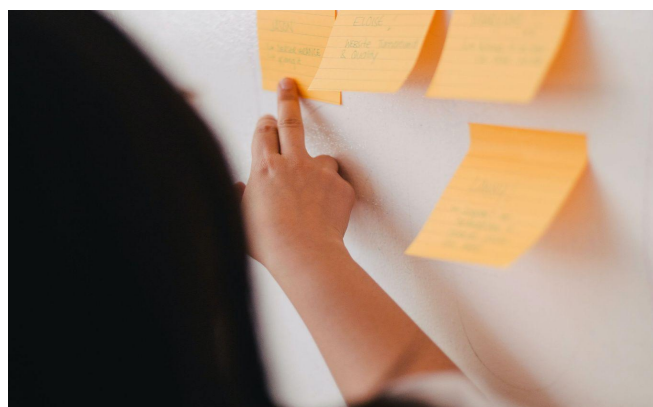
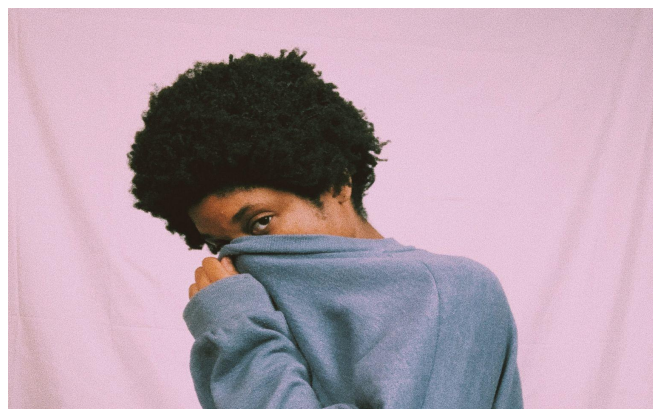
Startups and Taboo Health Issues

The early stages of new healthtech startups are research-rich environments that provide unique opportunities for public engagement. Health researchers working in these mission-driven ventures are leading research and innovation activities in an environment that is fast-paced, user-centred, interdisciplinary, and focused on societal impact.

Many new health startups are looking to tackle problems that are underserved by currently available products and services. With strong incentives to focus on neglected market opportunities, these ventures have the potential to have a profound positive impact on thorny problems. This is particularly the case with health issues considered ‘taboo’: problems that are rarely discussed, either in public or in private, and that stigmatise those that experience them.

By causing shame, often in both clinicians and patients, taboos are known to have significant impacts on health, illness and health-related behaviours. Because taboo health issues are not well-recognised by health systems, treatment provision can be inadequate.¹ Even when there are services available, stigma associated with taboo health issues can be a barrier to seeking help and engaging with care.² The internalised shame people experience when suffering from a taboo health issue means they are reluctant to talk about their problem to others, be it their health providers or friends and family, which may make treatment difficult or impossible, sometimes for many years.

Taboos are often the result of social marginalisation, whereby an aspect of one’s identity such as race, ethnicity, gender, class or age is stigmatised. The impacts of health issues (including, for example, mental ill-health, menopause, incontinence, fertility or IBS) can therefore be felt particularly acutely by marginalised groups.



As leading researchers Luna Dolezal and Barry Lyons have argued, ‘shame is so insidious, pervasive and pernicious, and so critical to clinical and political discourse around health, that it is imperative that its vital role in health, health-related behaviours and illness be recognised and assimilated into medical, social and political consciousness and practice’.³

Most startup founders understand the value of listening to, engaging with, and amplifying the voices of their customers. Indeed, as markets become increasingly crowded, building a deep and nuanced understanding of people’s needs is central to success. User engagement and co-creation — particularly with underrepresented groups — is a key part of ventures’ progress and development. Research and engagement through startups provide new opportunities to improve awareness about these issues, and generate improved health outcomes.

01

What we did as part of the programme

1.1 Zinc's activities

The project aimed to bring together early-stage digital health ventures, researchers, and those experiencing 'taboo' health issues in the development of new solutions. We looked to stimulate open and compassionate conversations about specific health topics that are often hidden or ignored.

Specifically, we wanted to:

- Create opportunities for underserved communities to engage with the research and innovation activities of new ventures.
- Enable researchers to gain applied experience working in ventures and with end users.
- Support founders of early-stage ventures to effectively and collaboratively tackle 'taboo' health issues.

Zinc supported seven of its portfolio ventures through this project, providing funding and a programme of support to maximise the impact and value of ventures' activities.

Hidden Health Stories

In addition, we felt it important to start wider conversations around these health issues. Collaborating with The Liminal Space, we created [a Hidden Health Stories Microsite](#) where people could anonymously share their taboo health experiences, either as a recording or in text. People shared stories of pregnancy loss, IBS, cancer, and mental ill-health (see p. 8). We summarised some of the learnings from these activities in short animated videos: [Video 1](#), [Video 2](#), [Video 3](#).

We also ran a number of events, including one on mental health and parenting. This particular event brought together a panel of professionals and people with lived experience, followed by an open dialogue between almost 200 attendees.

Throughout the programme, we aimed to bring together people interested in taboo health topics in various formats to enable mutual learning from the sharing of expertise and experiences.

We hosted a [podcast on health taboos](#), wrote an [article](#) about using stories to break the stigma and silence around taboo health issues, and invited people to an end-of-programme event to share learning.

While the topics we covered were sensitive and often difficult to talk about, we were struck by how eager people were to share and learn more.

“ I have had IBS for years. The symptoms have made my life quite tough at points but I don't feel able to talk even to the GP about them because I feel so embarrassed. I take way longer in the toilet than most people do, but feel ashamed and try to lie/come up with excuses rather than admit it. Often people ask about why I can't eat certain things and I try to skirt around the issues - how do you talk about bowel problems to someone you barely know?”



Anonymous user
Zinc's Hidden Health Stories website

1.2 Ventures' activities

As part of this programme, ventures focused on testing the need for their products, engaging with new user groups, understanding the best language to use, and maximising their impact. While there were commonalities with methods used, and a lot of shared learning, each venture followed their own path and had their own take-aways. Below is a short overview of their activities and key insights:

Ferly support people's sexual wellbeing.

Key findings: Cohort-based learning—that is, peer-to-peer sharing, co-production and reciprocal learning—is an excellent tool in supporting people's sexual wellbeing. It offers opportunities to share and connect with others, and to realise one isn't alone, something users find extremely valuable. Since the programme, Ferly has been working to apply these insights to their online sexual wellbeing courses.

Methods: Ferly developed and ran two cohorts of their pilot sexual wellbeing course and launched the 'Ferly Club', an online space for like-minded women and people with vulvas to connect with one another and share their stories and experiences. During and after their pilots, they analysed app data, conducted interviews, launched surveys, and ran focus groups.

Samson support people with erectile dysfunction.

Key findings: Samson's research suggested that their target users are not interested in talking to others about their erectile dysfunction, which influenced their decision not to pursue building a community. They also recognised the need to move away from medicalised language when talking about the issue, finding that their users preferred language relating to performance. The insights changed the way they present their products and recruit users.

Methods: Samson conducted surveys and tested various ways of engaging users online to find out about how men access solutions. They experimented with various types of content and messaging to find the most resonant and effective ways of communicating.



Focus Group Session by Tonus Tech. Photo: Tonus Tech

“ We changed our focus from medicalised language of dysfunction to one of performance improvement, and away from medication to an all-natural solution. We also understand our users to be older than we expected from previous research and surveys. Being able to address a wide audience through more organic channels, other than paid surveys, actually reflected the original users who informed my decision to pursue Erectile Dysfunction (ED) treatment instead of Urinary Incontinence (UI).”



Randall Yates
CEO, Samson

Parla support women who have experienced pregnancy loss.

Key findings: Most women receive no follow-up emotional health care after experiencing pregnancy loss and the solutions offered to them are inaccessible: often they are given pamphlets, directed to charities with long wait lists or left to do their own research during a time when they are extremely distressed and vulnerable. The team validated the need for a more proactive solution that supports women after loss.

Methods: Parla used multiple data-gathering strategies, ranging from analysing their in-app user-engagement data, to a survey, a co-creation exercise and in-depth interviews, in order to get to the heart of what women who have experienced pregnancy loss need, and to find out how their product can respond to those needs.

Bold Health support people with irritable bowel syndrome.

Key findings: People with IBS feel embarrassed, isolated and unsupported by the health system. They appreciate opportunities to come together with others who experience the same symptoms, and feel there is a need to increase social awareness of the disease.

Methods: They hosted events as part of a two-day summit about IBS and performed user interviews as well as surveys with users. The team used the programme to understand better the needs of people with IBS, to get data on improvements to their app and to establish new relationships with key IBS sufferers networks.

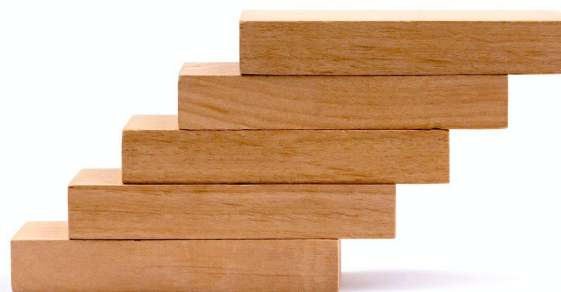
eargym support people with age-related hearing loss.

Key findings: Tackling hearing loss is made difficult by the taboo that it is a sign of frailty and ageing, meaning that most people wait 10 years before obtaining a diagnosis. There is great need for change, as the emotional and social impact of the impairment—including difficulties with keeping employment—is severe.

Methods: eargym undertook interviews and a survey to gain a better understanding of hearing loss as a taboo. The programme helped eargym to improve certain features of its app, contributed to testing its 'best-communication' approach, and defined its route to market.

Tonus Tech support people with mobility issues in later life.

Key findings: Tonus Tech realised the importance of creating trustworthy experiences and of the relationship between the patient and the health professional when it comes to mobility issues.



Methods: Tonus Tech undertook interviews, ran a co-creation exercise and a focus group with users. Their goal was twofold: firstly, they wanted to know how better information could help people engage with mobility health and act to delay mobility decline. Secondly, they wanted to find out how body augmentation technology could help people suffering from age-related mobility decline.

Method X support people experiencing mental ill-health.

Key findings: Method X found that help-seeking for mental health is difficult for the majority of people in the UK, for a complexity of reasons which vary across different demographic groups. They also validated that the mental health market is crowded and confusing, and most people will not find the solution that will work for them, at the time they need it. They identified the need for a brand new mental health solution that they are now working to develop.

Methods: Method X performed user research in partnership with Centric—a community research organisation that ensures its researchers are from the same community as they are researching—ran R&D ideation workshops, co-creation exercises and desk research, as well as performed a qualitative and quantitative survey into mental health in the UK. (For more information, see p. 11).



Much of the current resources available to women are not fit for purpose. By conducting a user-centric research like the one we developed we were able to uncover in a very short period of time the key needs loss mothers have and develop a pilot product to help them get the support they need.”



Lina Chan
CEO of Parla

Key Findings

2.1 Impact of health-related taboos

Taboos are enforced by shame and stigma. Evolutionarily, shame is a ‘policing tool’, an emotion that imposes a society’s rules for the good of the community; stigma is the external mark of that shame.⁴ But the taboos associated with particular health issues can be acutely detrimental to the health and wellbeing of those with stigmatized conditions. Going beyond the suffering caused by symptoms, this impact involves worsening physical, psychological and social outcomes. These three areas are inherently interconnected, with poor physical, mental and social impacts exacerbating each other.

Physical impact

Research in our ventures showed that people with taboo health conditions often suffer physically because they do not get the help they need. This can occur because they are too ashamed to talk about the problem and/or because the support from the health system is inappropriate, not suitably adapted, or nonexistent. On Zinc’s Taboo Microsite (see next page for more information), one person shared their experience of being dismissed by a healthcare provider despite reporting continuous pain:

“I have always dealt with severe pain during sex that has had a major impact on my relationships. When I

finally worked up the nerve to speak to a doctor about it, I was told that it was "all in my head".

Psychological impact

We found that the shame and stigma associated with the taboos makes the health burden heavier to carry, significantly impacting the mental health and wellbeing of the sufferer. On top of an unsupportive health system, people have to deal with feelings of shame, guilt and loneliness. As another user recounted:

“I felt very guilty, very ashamed, because I kept explaining myself. I kept thinking that maybe there was something I had done to lose my pregnancy.”

Social impact

Taboo health issues not only involve physical or psychological distress, but may significantly disrupt other areas of people’s lives such as their social relationships. Sufferers may have difficulties in socialising due to IBS-related issues or mental ill-health; they may have troubles dating because of sexual trauma, or problems keeping employment due to hearing loss. Such difficulties are compounded by the taboo. The person does not feel like they can share what they are going through, and therefore sometimes puts themselves through great pain in hiding their condition. One user commented about their experience of living with IBS:

“I was diagnosed with IBS in my mid-twenties. [...] It used to be so bad that I would be lying on the floor if I ate the wrong thing [...]. Which made some parts of life like dating particularly difficult because I didn’t want to be the fussy eater, or the one not going to drink or do anything. But if I did, I would either be in pain the whole night, or have horrible diarrhoea. [...] I used to kind of pretend or kind of go along with it, just because I didn’t want people to know. Even when I met my husband it took me about six months before I opened up to him.”

Working on the programme, we realised that little is being done for people suffering from these conditions, and, moreover, uncovered a powerful need to be heard, understood, and provided with solutions.



2.2 Communication, community and compassion

1. We need to open up difficult conversations

The stigma and silence surrounding many of these issues contributes to the physical and psychological distress of people living with hidden health experiences.⁵ Even the mere anticipation of shame when contemplating a disclosure of a taboo health condition to a healthcare provider can alter people's readiness to reach out for the help they need.³ Conversely, we found that opening up supportive conversations around these issues can positively impact those experiencing them – both in terms of direct emotional outcomes, and as a means of enabling them to get the right support. Many of the conditions explored by our ventures in this programme, such as age-related hearing loss and erectile dysfunction, are often left untreated for many years, partly out of self- and societal-stigma and a lack of open conversations about their symptoms and consequences.

2. Underserved communities need non-judgemental spaces to be heard and understood

People experiencing taboo health issues are often open to sharing their experiences, provided they are given a safe and supportive environment in which to do so. With few people to open up to about their conditions, participants consistently reported valuing being heard and feeling understood during the programme. For example, on a course about coping with pregnancy loss run by Parla, an anonymous user said:

“The massive thing for me was not feeling alone, like a social leper. [It] was so much more beneficial than I could ever imagine.”

Parla and Ferly found that people particularly appreciate safe and judgement-free spaces to share their experiences. Taboo health issues are often not easy to talk about, and emotionally loaded for all parties involved, meaning that these spaces worked best when facilitated by a compassionate and empathetic expert.



Talking helps

Recognising the transformative power of sharing and reading about personal stories, Zinc created a microsite where people could anonymously post their hidden health experiences. Research has found that online disclosures can help, among others, people suffering from mental ill health,⁶ miscarriage⁷ and sexual violence⁸ to feel less stigma and shame. As we have seen with the the #metoo movement, disclosures lead to more disclosures, and a greater public awareness of the issues at hand. While the microsite was a very small-scale project, it nevertheless gathered over 20 stories and was visited by more than 1000 users. The stories shared were very diverse, touching on pregnancy loss, cancer, IBS, difficulties with sex, trauma and fibromyalgia. Each one was unique, but they were united by a common theme: frustration about imposed silence, and the inability to tell those around them about what they are going through. This shows, as Luna Dolezal has described elsewhere, a powerful need to overcome shame in order to validate one's own identity.⁹

“ We heard many times of the need for people's experiences to be heard, not only for their issues to be treated.”



Marianna Recchia,
Co-founder of Tonus Tech

3. Compassion and empathy are key

The stories we received through our hidden health stories microsite showed how transformative compassion and empathy — from health care providers, friends, family or even strangers — can be. Sensitive responses help counter the stigma and shame associated with the condition and in doing so help the person to feel better, and sometimes even to get the help needed. As one user commented on the microsite:

“I was really struggling after my son was born. Everyone around me just dismissed it as ‘baby blues’, and then so did I. After 9 months of crying several times a day, not sleeping more than 2 hours a night and feeling suicidal, I broke down in the supermarket one day. A kind lady in the shop took me in her arms and helped contact the doctor. I finally got the medical support I’d actually needed for months.”

4. Social networks are important

When talking about taboo health issues, there is a risk of overlooking the important roles that social networks play in tackling individuals’ health issues. Friends and family are often key in prompting diagnoses and offering support. Samson, through their user research, found that it was not uncommon for people to complete a survey on erectile dysfunction on behalf of their partner. Similarly, eargym noted that many people are made aware of their hearing loss by family or colleagues. Method X found that friends and family are the first resource to whom people turn when in crisis.

While supportive interactions can be transformational, unsupportive comments or reactions can of course perpetuate feelings of shame and isolation:

I have always struggled with my mental health. “Grow up.” “Calm down.” “What’s wrong with you?” All of these [reproaches] haunt me, constantly shaming me for my brain which I can’t help. It’s like I’m constantly running away from this monster and sometimes I manage to run far enough but sometimes I trip and it catches me.



The physical, psychological and social difficulties brought about by taboo health problems are often condition-specific, as are potential ways to overcome them. However, the majority of sufferers have in common the feeling of shame, loneliness, and being misunderstood. One important way to help people overcome those feelings, as realised by more than half of the ventures participating in the programme, is by providing opportunities for peer-to-peer sharing as part of their solutions. Creating space for connection with others suffering from similar conditions and with similar experiences helps counter this shame and loneliness, allows users to exchange coping strategies, and facilitates resilience. This on its own is an important step in working to address the health issue.

While opening up conversations will rarely be sufficient, it is important as a first step towards enabling the right support to be delivered. We explore this more in a [podcast with Linnea Dunne, writer and podcaster, and Dr Anna Hushlak from Ferly.](#)

“The impact on participants themselves and value creation from sharing and connecting with others like them and knowing they aren’t alone has been huge.”



Dr Anna Hushlak
Co-Founder & Chief Scientific Officer, Ferly

5. Stigma and shame are associated with a diverse range of health issues and areas

Taboos affect an extraordinary range of health issues and people, each with their own experiences and desired solutions. While we saw many common themes across the various health areas covered by this programme, we also found a need for nuanced discussions. For example, peer support was seen as more desirable for some conditions (e.g. pregnancy loss) than others (e.g. erectile dysfunction). Some conditions were also seen as being easier to speak about publicly (e.g. mobility) compared with others (e.g. IBS), and among particular audiences (e.g. when taking into account differences across age and gender). These subtleties have tangible consequences for startups working on solutions for specific health conditions, in terms of the ease with which they can generate a public conversation on their health subject, dealing with marketing bans from mainstream marketing channels, etc.

6. Community researchers are key to conducting great research with underserved communities

This programme aimed to engage two types of underserved communities in user research: people suffering from taboo health conditions, whose needs are unmet by the health system, and people that are often ignored by current digital solutions research: ethnic minority groups, older adults, and people from socioeconomically disadvantaged backgrounds. We discovered the great, and untapped, potential of using community researchers—that is, researchers that are from the same community as they are researching—to conduct health innovation research with ethnic minority groups. By asking questions our startups wouldn't have thought of asking, these researchers provided fresh, rich and actionable insights. From such efforts, we learned that people suffering from taboo health conditions are really eager to participate in the co-creation of potential solutions.

7. Carrying out research in early-stage ventures comes with its own challenges - and rewards

For most of the ventures the user research was very helpful, and in some cases even transformative, for the company. This confirmed to us the importance of supporting startups to integrate user research and researchers from the beginning of their enterprises.

However, the path of producing useful work was not without its challenges for the researchers, challenges which were over and above the sensitivity of the topics covered.



Researchers were surprised by the difference between the slow pace of academia and the quick-moving environment of startups. They needed to adjust and, sometimes, develop new ways of working. The discrepancy between what needs to be done and the limited resources available in ventures was a common issue. For the most effective working, they emphasised the need for clear and open communication from the start, allowing for an in depth understanding of the company's aims, plans and ambitions. Confirming the utility of the researcher-startup facilitation provided by Zinc, researchers also appreciated the presence of a neutral facilitator to help with making adjustments to the new environment, and to assist with any unexpected challenges.

Overall, researchers shared their satisfaction at working on taboo health topics and seeing the results of their work translated into concrete product recommendations that are transforming people's lives. With reciprocal benefits for all involved, we found an immense value in bringing together researchers, startups and users to work to tackle taboo health issues.

“ The level of insight we got was incredible (...). We handed it over to the people who knew best and they carried out conversations in a way we probably wouldn't have and managed to get information that we probably wouldn't have.”



Deborah Coughlin
Founder of Method X Studios

03

In Focus: Tackling Inequalities in Health Provision

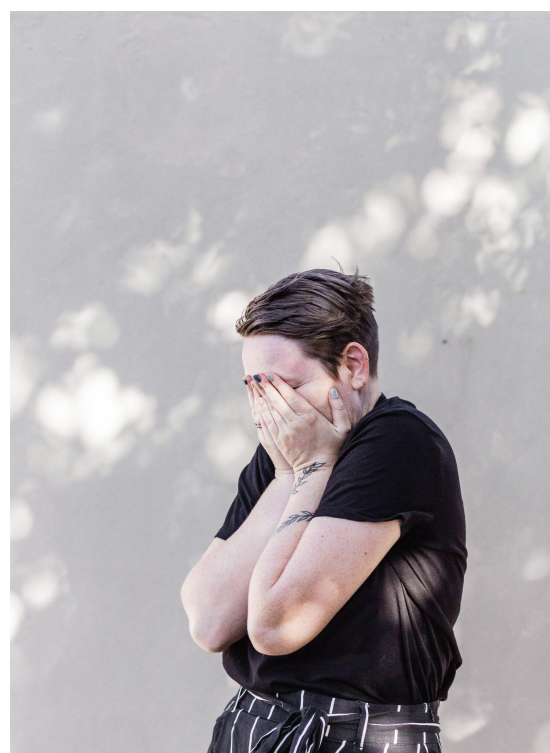
The goal of the programme was to involve users and researchers in the research and development of solutions to health issues, as well as to stimulate open and compassionate conversations about specific 'taboo' health topics. Method X, who support people experiencing mental ill-health, conducted research into the link between marginalisation and mental health.

Although it is widely acknowledged that poverty and disadvantage increase the likelihood of mental health problems, people from lower socioeconomic brackets, BAME backgrounds, and LGBT+ communities are less likely to access mental health support. Method X wanted to learn about this phenomenon in order to improve engagement with disadvantaged communities.

Working with Centric, a community research organisation, and a social scientist, they ran ideation workshops and co-creation sessions, commissioned qualitative research, undertook literature reviews, and tested their ideas with users, generating findings that shaped the direction of their business.

They found that community researchers were key to the success of the project, as many left behind groups felt over-researched by people unlike them and with different lived experiences. Most importantly, they identified a significant treatment gap in mental health provision, whereby those needing help most do not receive it. Running interviews and workshops, they identified lack of access, stigma and distrust of services as key barriers.

They also learned that people valued non-judgemental spaces, and that reading other people's stories can help people to make sense of one's own mental health. Market research confirmed that existing solutions did not address these issues, meaning that low earners are the least likely to have support. The findings contributed to the development of



“ People want trustworthy information from other people that look and sound like them. **”**



Dr Iain Jordan

Chief Medical Officer, Method X Studios

a [novel, personalised service](#) for those suffering from mental ill health, which supports people through behaviour change stages more quickly, and matches people to solutions more effectively, than the current system.

Behind the report

Zinc

Zinc exists to build and scale brand-new ways to address the world's most important societal problems. Our approach empowers talented and motivated people to experiment their way to impact at scale in our mission areas.

Since we launched in 2017, we have been developing a unique ecosystem of diverse talent across many sectors, disciplines and countries - mobilising people around common missions and building scalable solutions to social problems.

Each of our programmes provide unique opportunities for research, innovation, and public engagement. This report presents the key activities and findings from our Taboo Health Programme, funded by a Public Engagement Award from the Wellcome Trust.

Programme's Ventures

FERLY

Ferly

Ferly is empowering women and folk with vulvas to have healthy, confident and pleasurable sex. Ferly uses cognitive behavioural therapy and other techniques to help its users overcome sexual difficulties or to become more aware of their bodies and discover what works for them

Founders:



Dr Anna Hushlak



Billie Quinlan

eargym

love your hearing

eargym

eargym is discovering how immersive auditory training can best address the effects of age-related hearing loss on our social interactions and cognitive decline, globally. They are helping people maintain their hearing as they age allowing them to continue to be socially engaged and remain active.

Founders:



Amanda Philpott



Andy Shanks

TONUS

Tonus Tech

Tonus Tech is designing augmented wearable solutions that combine elements of exosuits, activewear and design to provide assistive torque.

Founders:



Dimitris Xydias



Marianna Recchia



Ahmed Wobi



Method X Studios

Method X wants to democratise good mental health, and end the mental health poverty gap. They are working on cracking scalable prevention of poor mental health for a mass-market.

Founder:



Deborah Coughlin

Samson

Samson

Samson is a digital health platform for men focused on drug-free, non-invasive interventions for sexual dysfunction and improving genitourinary health. Samson are increasing understanding of what healthy looks like and providing the tools for men to achieve this.

Founder:



Randall Yates

Bold Health

Bold Health

Bold Health is a virtual therapeutic care provider revolutionizing the treatment of digestive conditions through comprehensive patient-centric care.

Founders:



Elena Mustatea



Jossy Onwude



Parla

Parla is a digital health company revolutionizing access to reproductive health. Through group programmes led by experts in the field of fertility, psychology, nutrition and wellbeing, Parla empowers women with comprehensive mind and body techniques so they can better manage their symptoms and build confidence.

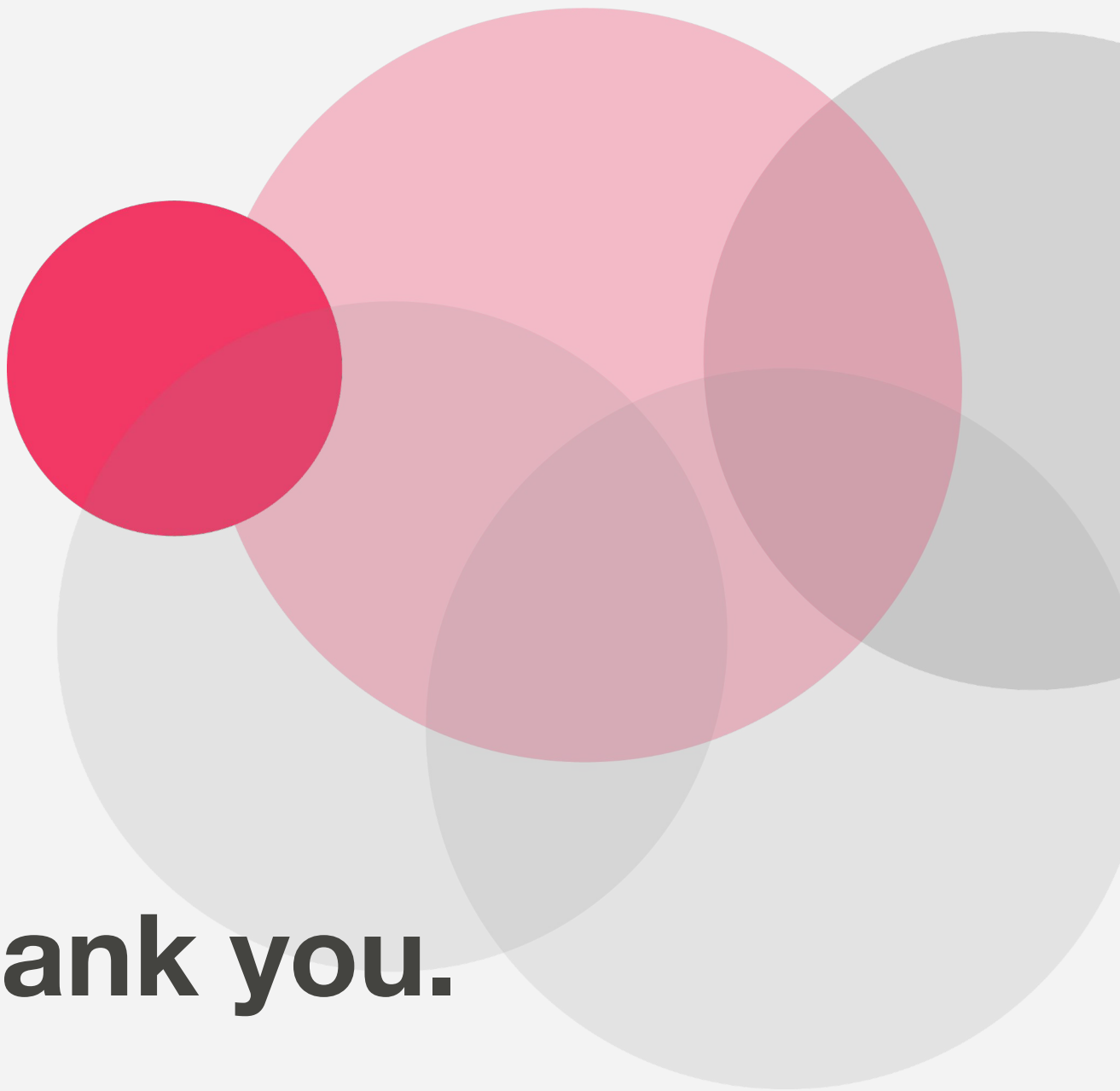
Founder:



Lina Chan

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Thank you.

To find out more please visit www.zinc.vc or
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