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Depression Detectives: A methodology for online co-created research

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Depression Detectives: A methodology for online co-created research.

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Plain English Summary

Depression affects many people, and researchers want to help. Data scientists use powerful computers to find patterns in large data sets. While data shows what has happened, it is not very good at working out the reasons behind it. People who have experienced depression can have insights that researchers might overlook. When researchers and other people work together, it’s called ‘co-created research.’

We ran a project with data researchers and people who'd had depression. They held online Q&A sessions to learn about research and the science of depression. Together, they thought of many potential research questions. They explored these and chose one: "Do people report all episodes of depression to their GP? And if not, why not?". Then, they decided which research methods to use.

The data scientists checked the UK Biobank, a large health database. They found that 67% of depression episodes were missing from medical records. People had not told their doctors.

The lived experience participants did discussions and surveys to find out why. They found that people only visit the GP for about half of their episodes. Reasons for this included feeling hopeless, thinking the GP wouldn’t help, and not wanting antidepressants.

The lived experience participants enjoyed the project. They appreciated the chance to talk to others and reflect on their experiences. They valued the opportunity to do real research, although it was sometimes stressful. The researchers learned more about patient perspectives but found the process hectic. We would like to do it again, but better.

Abstract

Background: Incorporating lived experiences into research is claimed to enhance depth, relevance, real-world applicability and equity. However, data scientists have been slower to adopt this approach than other health fields. The "Depression Detectives" (DD) project aimed to bridge this gap by connecting Big Data researchers with individuals who have lived experience of depression. Depression is both a significant global health issue and a deeply personal experience. Feelings of isolation often drive people to seek information and support online, making this project's digital presence particularly relevant.

Methods: Building on research methods developed in Parenting Science Gang, we conducted a co-creation project within a private Facebook group from February to September 2021. Seventy individuals with depression and thirty data science researchers participated in discussions and chose a research question. Together, they designed and implemented a survey and focus group discussions exploring health-seeking behaviours and under-reporting of depressive episodes to GPs. Concurrently, a PhD student analysed UK Biobank data for discrepancies in depression reporting.

Results: In the UK Biobank, 67% of individuals whose questionnaire responses indicated depression had no GP record of it. Similarly, 84% of DD participants reported visiting their GP for half or fewer of their depressive episodes. Key barriers included stigma, dissatisfaction with healthcare, and a preference for non-medical interventions such as private counselling, mindfulness, and exercise. These alternatives were perceived as addressing the root causes of depression.

Participants described the research process as rewarding and empowering, noting it broadened their understanding both of depression and their own experiences. Researchers valued the insights gained, but found the process demanding.

Conclusions: This project demonstrates the value of incorporating lived experiences into mental health research through co-creation. Lived experience participants contributed unique perspectives that differed from those of university researchers. By combining these insights with big data analysis, the project generated findings that better reflect real-life experiences, enhancing their applicability to personalised mental health care.

Participants found the process to be 'quasi-therapeutic' and advocated for healthcare systems to adopt diverse, holistic treatments for depression. These findings support inclusive policy development and underscore the importance of epistemic justice and democrative knowledge production.

Keywords

Depression, Co-creation, Citizen Science, General Practitioners, Data Science, Big Data, Patient Involvement, Mental Health, Co-production, Patient and Public Involvement.

Background

Patient and Public Involvement in Research

In this paper, we use the term Patient and Public involvement as an umbrella to cover all collaborative efforts between the research community and individuals such as patients, carers, advocates, service users and community members (1). Effective PPI values all contributions, ensuring people have a meaningful say in research and influence its outcomes, as set out in the UK Standards for Public Involvement (2). PPI is often described as a spectrum or ladder, ranging from 'Inform' at the bottom (sharing information about the research), through 'Consultation' (seeking feedback), to 'Involvement' (integrating patients into the process), 'Collaboration' (partnering with patients), and culminating in 'Empowerment' at the top (with patients initiating and leading the research) (3)

This approach also supports epistemic justice (4), the idea that multiple perspectives must be recognised to understand what is going on, by ensuring that individuals with lived experience are acknowledged as legitimate knowers whose insights enrich and challenge dominant research paradigms (5)

Meaningfully incorporating lived experiences into research enhances depth and relevance by providing insights that might otherwise be missed (6). It also ensures interventions are grounded in real-world contexts, ultimately producing more effective and sustainable results (7). Furthermore, it fosters inclusivity, promotes equity and diversity, and empowers participants by involving them directly in the research process (8).

PPI in health and social care research has expanded significantly in recent years (9) rooted in the understanding that it is important, expected and possible across all research types

(10). Funders and policy-makers promote PPI both because it leads to better research outcomes and to social justice (10). Consequently, funding and policy levers have been introduced to support it (11,12). For example, UNESCO's Open Science recommendations (13), emphasise the importance of community engagement. Similarly, Research England's £6 million Participatory Research Grants, launched in 2021, highlight substantial investments in this area (14). Organisations such as UKRI (11), the Wellcome Trust (15), and the NIHR (3,9) now mandate the inclusion of lived experience in all mental health research. The shift is also evident in research infrastructure, as mental health charities like MQ (16) and UKRI's Mental Health Platform (17) have both incorporated PPI components. Additionally, the upcoming REF 2029 emphasises 'Engagement and Impact' with 25% of its weighting dedicated to these aspects (18).

However, some have criticised some PPI efforts as shallow or tickbox exercises, working with the 'easiest to reach'(19), and not challenging or addressing power dynamics. Many researchers lack the knowledge, time or skills to involve patients or publics in significant or meaningful ways (20). Furthermore, even the term PPI is a contested (21), and terminology use varying greatly across the sector and between topic areas. This project aimed to respond to that challenge by offering a practical, supported model for deeper engagement.

Role of Big Data in Mental Health

This project's key focus was to bring together Mental Health Big Data researchers with people who have lived experience of depression. Big data plays a crucial role in understanding health trends. By combining large datasets from diverse sources, researchers can identify patterns and risk factors that might not be evident on a smaller scale (22). This is crucial for developing effective public health strategies (23). However, the field has been slower than more clinical or social science areas of health research to incorporate PPI (24).

Nevertheless, while these large datasets can reveal correlations, they often lack the nuanced context required to understand causation (25). They can tell us WHAT happened, but not always the reasons behind it. Contrastingly, PPI approaches excel at providing context and insights into the nuance of patient experiences, helping to illuminate WHY things are happening.

Researchers use various anonymised public data sources, including census data, electronic health records and prescription data (26). These are complemented by volunteer contributions from cohorts such as the UK Biobank (27) and Generation Scotland (28), which provide additional data, including genetic information and self-reported health questionnaires. Combined, these data provide valuable insights into the prevalence and triggers of ill-health (29) and hold promise for personalised medicine approaches (such as those being advanced by the Wellcome-funded AMBER project (30)).

In this project, we piloted the use of co-creation with patients as a way to bring insight and context to the interpretation of Big Data results. We also wanted to help focus Big Data's attention on questions that are important to people who experience depression.

Overview of Depression:

Major Depressive Disorder, often referred to simply as depression, is a mental health condition characterised by long-lasting, persistent low mood. Symptoms include poor concentration, excessive guilt, hopelessness, thoughts of death, disrupted sleep, changes in appetite or weight and low energy (31). It affects every aspect of the person's life, including their long-term health, social wellbeing, family relationships, education and career (32). It can be categorised as mild, moderate or severe based on symptom severity and impact on everyday life. Depression is ranked by WHO as the single largest contributor to global disability (7.5% of all years lived with disability in 2015 (33)). In the UK, approximately 1 in 5 adults experience symptoms of depression at some point in their lives (34)

Online engagement

Depression can lead to isolation, making daily activities and social interactions challenging (35). This internal struggle often drives individuals to seek online support for information and peer connection (30), which has been shown to improve symptoms and enhance empowerment (37). However, the quality of online resources varies widely.

The lead author (SC) previously developed an online co-creation research project for parents of young children (38) who can experience similar problems with leaving the house, personal care and accessing meaningful adult interaction. Furthermore, at the time of this project, some COVID-19 restrictions were still in place (39), and many people were still socialising and working remotely. The online model of engagement was a way to integrate lived experience into research, under the constraints of ongoing social distancing measures.

The Depression Detectives Project

The funding for this project came from research grants [UKRI Medical Research Council (MRC) and European Commission Horizon 2020]. The Patient and Public Involvement Co-ordinator employed on these grants (IB) had previously been involved in Nappy Science Gang (40) and Parenting Science Gang (38) and recognised an opportunity to bring the same co-creation methodology into mental health data science.

This project was envisioned as a short pilot study (8 months) to investigate whether the techniques used in Parenting Science Gang (which lasted 2 years) were transferable to a different context. We wanted to provide proof of concept for meaningfully involving people with lived experience in big data research. Although similar in many ways to its predecessor, one key point of difference between the projects was the recruitment of researchers. For the Parenting Science Gang, the topics were chosen by the lay participants, and then a researcher had to be located and invited to join the project. For Depression Detectives, the partnership with data science researchers from Edinburgh Neuroscience [an

interdisciplinary, cross-college community at The University of Edinburgh (41)] was in place from the beginning. This lightly constrained the research direction, but also provided opportunities for co-creation from the very beginning.

The project was run as a partnership between Edinburgh Neuroscience, the Patient and Public Engagement Coordinator, and social enterprise Science is People Ltd (SiP). Researchers and staff at the department took an active part in the activity, but much of the day-to-day facilitation was carried out by project staff working for SiP. One member of staff has extensive experience in public engagement with science, one is a social science researcher with counselling expertise, and one had a background in comms and online community management. Several members of staff across both organisations had lived experience of depression and were frank about their dual role and experiences in group discussions.

Methods

Ethical Considerations

Ethical oversight was secured through Edinburgh Medical School Ethics Committee (EMREC), with ethics permission reference 21-EMREC-004_SA2.

However, achieving this ethical clearance was challenging as EMREC typically does not usually assess PPI/co-created research projects.

Once the process began, it became clear that our participants were considered potentially vulnerable, so various safeguards needed to be put in place (see Table 1). These included a lengthy Patient Information Sheet, which (for technical reasons) had to be presented on a separate system (Jisc surveys). This created an additional, time-consuming sign-up step,

which we suspect was a significant barrier for some potential participants. The ethics board also raised concerns about the use of a private Facebook group, specifically regarding accessibility and anonymity, as participants were required to have a Facebook account to participate, and these accounts are typically linked to their real identities. An exploration of these and other ethical issues is presented in Table 1.

Nevertheless, this project (amongst others) has stimulated ongoing efforts at the University of Edinburgh to improve ethical oversight for PPI initiatives, including the establishment of a dedicated ethics board (in progress)

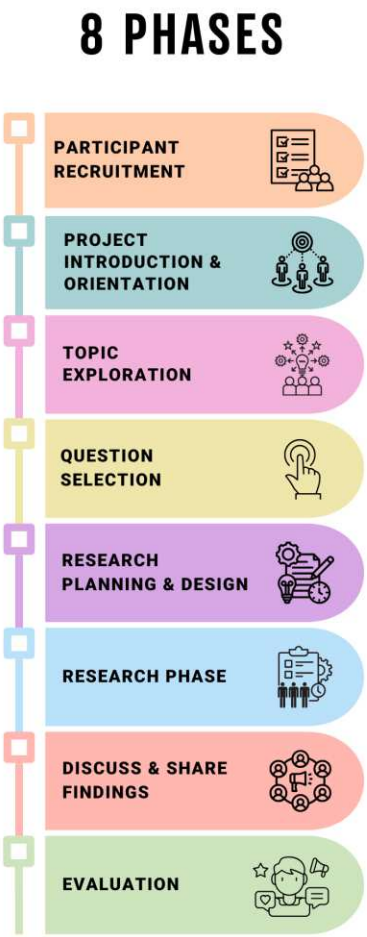
Setting

As project organisers, we chose to conduct the majority of this project in a private Facebook group. At the time, most social media users used Facebook (83%)(42), with 61% of UK adults visiting it daily (43). However, it's worth noting that the social media landscape has since evolved, with platforms such as TikTok, Snapchat, and Instagram becoming increasingly popular, particularly among younger generations (44). The predecessors to this project (Parenting Science Gang (38) and Nappy Science Gang (40)), were also hosted on Facebook, benefiting from the vibrant community of parents and new mothers that could be found there. To give the project a public presence, a project blog was also set up to host project details, progress updates and anonymised Q&A transcripts.

Process

The project used an 8-stage process (see Figure 1)

Figure 1: The 8 phases of the project.



Phase 1: Participant recruitment

We recruited lived experience participants [from this point forward referred to as 'participants'] through various channels, focusing on those over 18 who had experienced depression or worked with affected individuals, but who were not currently depressed or in crisis. Although we aimed to recruit Scottish participants, we were open to others from any location. Recruitment channels included mailing lists, participants from previous projects, personal networks and social media/local charities (see table 2). Sign-up forms included questions about participants' views on mental health research and their confidence in

accessing research and expressing disagreement with healthcare providers, which aided later evaluation.

Researchers were recruited from the lead Patient Involvement Coordinator's research group and through "coffee morning" sessions, where they learned more about the project.

Table 2: Recruitment Methods

Edinburgh Neuroscience mailing lists
Previous PPI activity participants
Participants from similar projects (Parenting Science Gang, Nappy Science Gang)
Team members' and researchers' Twitter feeds
Local organisations (e.g., mental health charities)
Personal networks via Facebook, LinkedIn, and email
University of Edinburgh community and PPI email lists
'Coffee' Zoom drop-in sessions for University of Edinburgh staff, especially Edinburgh Neuroscience

Phase 2: Project Introduction & Orientation

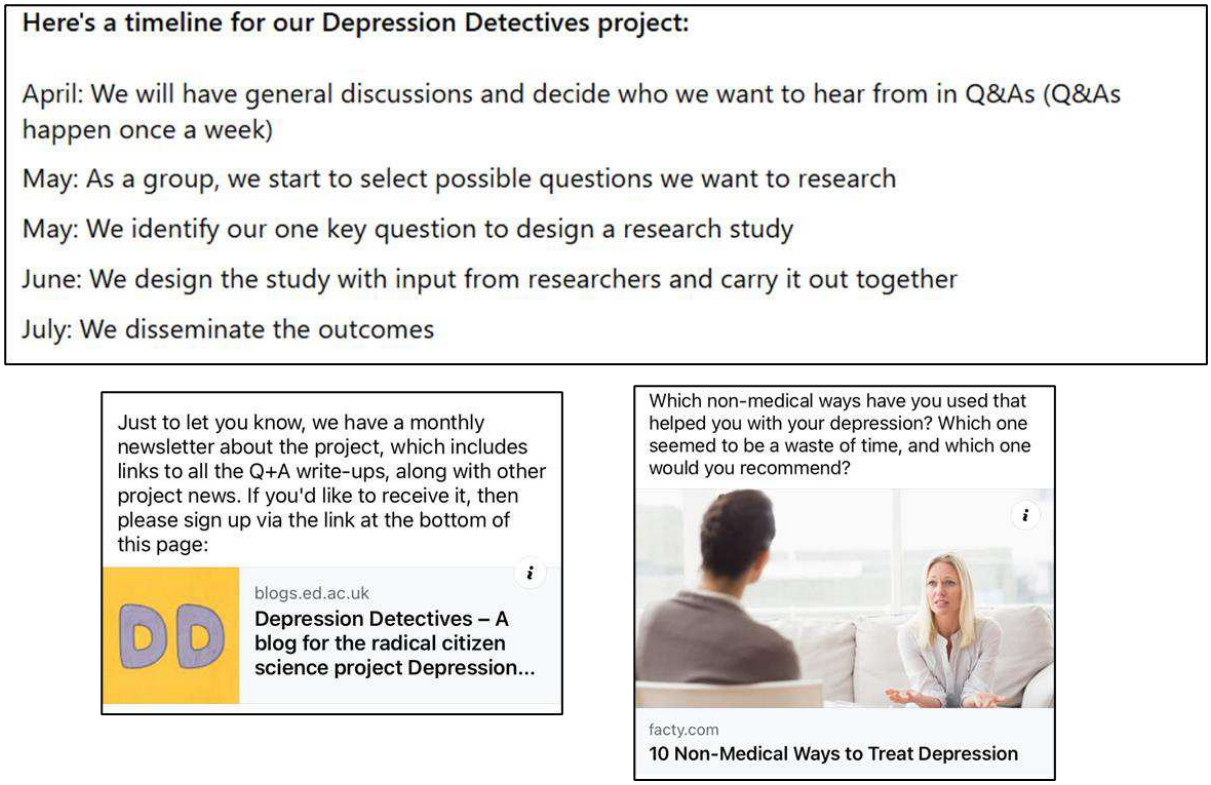
This phase involved getting to know each other and the project, as well as establishing our interaction style (see Figure 2). We posted frequently in the group to clarify our goals, opportunities, and, importantly, our constraints. Post types included:

- explanation of co-produced research,
- overviews of previous projects,
- participant roles and expectations,
- survey reminders,
- tips on notification settings.

We repeated the same topics several times to ensure they were seen. In previous projects, participants often said, "We wish we'd known X," despite multiple posts on that very topic. We also asked participants to help us edit our provisional group rules (used in previous projects) and suggest any new rules they thought would help ensure we had productive and collaborative discussions.

Our tone was chatty and encouraging, prompting participants to interact, which, of course, was the project's primary purpose. Engagement, especially comments, also boosts the Facebook algorithm and improves the visibility of posts. Nevertheless, based on previous experience, we knew it was essential to use a variety of post types to guide people from lurking towards active participation. Polls were used for quick, simple interactions (e.g. best time for Q&A session, pick a topic from a list), whereas simple open-answer threads were used for quick text-based answers (e.g. introduce yourself, what topics you are most interested in). We combined these with more topic-based discussions, which featured content such as articles (journal articles, NICE guidelines, popular science and news articles), and creative content (podcasts, videos, art exhibitions, film festivals) that could be discussed from a variety of angles (see figure 2).

Figure 2: Example Facebook posts during the introductory phase



This phase also included our first Q&As. These were a key part of our method, involving a researcher coming online at a specific time, briefly introducing themselves and their topic, and then providing text-based (typed) answers to our participants' questions. After a trial of posting these in the main Facebook group, we decided to move them to separate Facebook groups, making them more of an ‘event’ and avoiding cluttering up the main space. Initial sessions explored perspectives on depression, including clinical psychology, brain imaging, social anthropology, and treatment options.

Phase 3: Topic Exploration

This phase focused on expanding topics and generating new ideas. We assumed participants understood our goals, but continued sharing reminders and overview links. We arranged more specialised Q&As (e.g., depression and sleep, pregnancy and childbirth, COVID) to introduce participants to available researchers and potential research methods.

Before each Q&A, we shared posts about the topic and the researcher, encouraging discussion and collecting questions in advance from those unable to attend. At the start of the Q&A, the central project team helped break the ice by asking basic questions. They then actively took part, sharing their own (varied) views and experiences. They modelled asking clarifying (‘stupid’) questions and saying ‘I don’t understand’, as well as ensuring comprehensive coverage of the topic (the what/how/why of the research). After each Q&A, we cleaned up and anonymised the transcript, posting it on the project blog as a discussion resource for the group, a dissemination tool for the researcher and as an ‘advert’ on social media to attract new members.

Alongside this, we continued to facilitate online discussions, encouraging participants to start suggesting research questions.

Phase 4: Question Selection

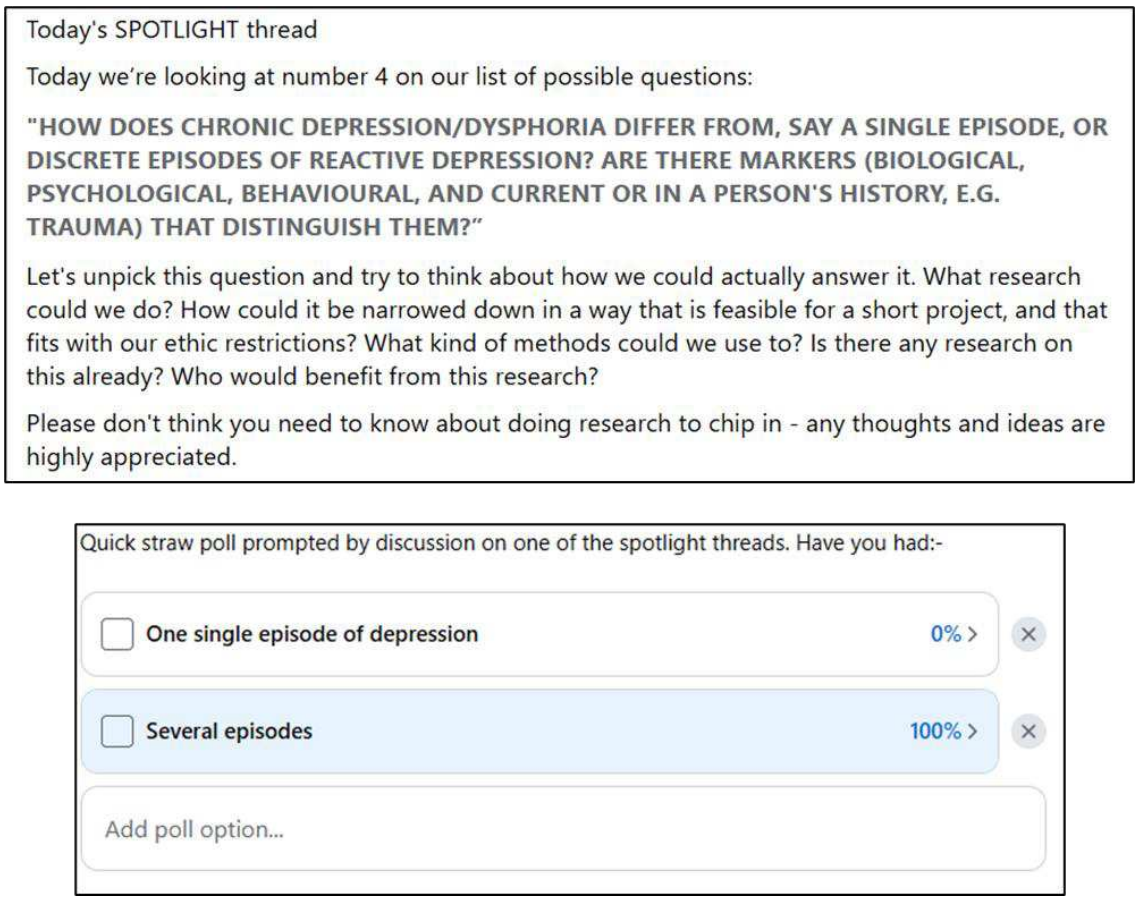
This was a narrowing phase, after the expansiveness of the question-generating phase. During this phase, the group collaborated with researchers to select a question and start designing a project that fit within the budget, time, and practical constraints.

The group generated 59 potential research questions. We listed them all in a big post, in the exact words of the questioner, and then repeated them below the post, each one as a separate comment. This allowed a separate ‘sub-thread’ to form under each question. Throughout the week, we encouraged active discussion and shared resources, like how to conduct Google Scholar searches and understand cohort studies. We also kept reiterating our timelines, where we were in the process and the next steps. Members then had a further week to vote for their top three choices, using the 'reaction' buttons. This method of voting (range voting) is used to find the solution which is palatable to the greatest number of voters.

The vote resulted in a top ten list (see Additional Information 1). Daily ‘spotlight’ threads followed, where we discussed each of the top ten questions in turn, exploring why they

interested us and any links to previous discussions. We also discussed the implications of the research, how it might be researched (methods), what resources and researchers we had available and considered what might be feasible within our timescales and logistics. (Please see the discussion section for more on this process and why it was designed like this.) The quietest spotlight thread had 16 comments, and the busiest one had 55 comments.

Figure 3: Example spotlight thread and follow on poll.



After ten days of 'spotlights' and other conversations alongside those threads (see Figure 3), we then opened voting on the top ten, using the same process as above (post with each question as a comment and range voting via the 'react' buttons). The winning question was: "How does chronic depression/dysphoria differ from a single episode or reactive

depression? Are there markers (biological, psychological, behavioural, historical, e.g., trauma) that distinguish them?"

Phase 5: Research Planning and Design

In this phase, we explored the chosen research question from as many angles as possible. Participants shared their interests and expectations, and we discussed terms and words related to the question, comparing scientific and personal definitions. We shared relevant papers and discussed the findings, exploring their implications for us and this project.

A group poll revealed no one had experienced a single episode of depression, sparking several discussions on whether multiple episodes are more common or if people who experienced a single episode were less likely to ‘identify’ as a person with depression and join a project like this. We also debated the term "episode," with several members expressing that the word didn’t characterise their experience at all. (See results section for more details and quotes).

We held a Q&A with three data researchers about using cohort study databases, and another with a research consultant to explore non-data science options and discuss what participants wanted to get out of the research. These sessions enriched our discussions and encouraged researchers to come into the Facebook group to address participants’ queries.

This phase mirrored the two previous ones, expanding outward in all directions and then refining ideas until the focus narrowed to two key research strands. The revised research question became: "Do people report all episodes of depression to their GP? And if not, why not?"

The plan evolved into two parts:

- **Data Science Research:** Conducted by a PhD student using UK Biobank data. She compared self-reporting of depression (sign-up questions and completion of

standardised depression screening questionnaires) to codes relating to depression in Electronic (GP) Health Records.

- **Social Science Research:** Surveys and Focus Groups led by the participants to explore experiences of ‘depression episodes’ and why/how/where people seek help.

Phase 6: The Research Phase

Although the whole project was co-created research, this phase was where the research participants actually co-designed and carried out specific research activities. Facilitated by social science researchers, participants crafted prompt questions for focus groups (targeted discussion threads). These included:

- What are “episodes” of depression for you? Does speaking of “episodes” make sense to you?
- What went on for you when you tried to decide what kind of help to seek? If you went to your GP, what made you decide to go? If not, did you consider going? Why did you decide not to?
- What has your experience with primary care staff (doctors, but also receptionists) been like? What worked and what would you like to be different?
- What kind of help would you like to be offered when experiencing depression? What would be most helpful to you, and why? Could all of this be offered by GPs? What has been offered to you but was not helpful?

At this point in the project, we focused primarily on these targeted discussion threads [focus group questions] and used numerous reminders to encourage participation.

Responses from these discussions formed the basis of a co-produced survey (see Additional Information 2). The group wanted to distribute this widely, but that would have required an ethics amendment, which would have delayed the process by months, making it infeasible (We only had 2 months left). We were therefore limited to the group’s ~100 members. This is

a common challenge in co-created research, where the question and method do not exist at the start. A completion deadline for the survey was set, and a staff member analysed the combined focus group and survey findings.

The "big data" strand, managed by a PhD student, was less interactive. For ethical reasons, group members were unable to assist with the analysis of UK Biobank data (45). However, we were able to discuss things like the 96 different codes that are available to GPs to record depression; the measures that are used, such as the Patient Health Questionnaire (PHQ-9) screening questionnaire (46); and the questions that are asked in UK Biobank questionnaires (such as “How many periods did you have in your life lasting two or more weeks where you felt like this?”). Otherwise, the student worked independently on the data analysis and later presented her findings to the group.

Phase 7: Discuss and Share Findings

We posted the results from both research strands into the group (survey & focus groups results, and PhD student Biobank research findings). We did this both as summary reports and as individual graphs and charts to encourage engagement and discussion. Group members discussed if they found anything surprising about the findings, and how the overall findings compared to their own experience.

We also asked the group to consider dissemination - who they wanted to inform about this research, and what they wanted to convey to them. The group identified several key audiences:

- GPs and healthcare professionals
- Individuals with lived experience of depression
- Policy-makers (broadly defined)
- Data science researchers

A staff member created infographics for each group, highlighting key messages, and we asked participants to help share them.

Phase 8: Evaluation - public and researcher

Survey for lived experience participants

The survey consisted of 18 questions, with a mixture of qualitative and quantitative types. (see Additional Information 2). It requested some demographic data, their opinions on scientific research, and their approach to managing their own mental health. Additionally, it inquired about the perceived usefulness of various activities within the project and their overall satisfaction with their experiences.

Semi-structured interviews with lived experience participants

Four participants were interviewed by one of the co-authors and project staff members (CK), who is an experienced qualitative researcher. The participants were selected by the project team to represent a spectrum of activity in the project, ensuring a range of views and experiences. Everyone who was invited agreed to be interviewed. Interviews lasted approximately 45 minutes and were recorded on Teams. The interviewer transcribed them and analysed them thematically. The prompt questions were about:

- Their background and previous experience in research
- Their motivations for getting involved in this project
- Their experiences of the project - both good and bad
- What they thought they had got out of the project - learning, feelings about science, etc.

Survey for researchers

The survey for researchers consisted of 8 questions, mostly open-text responses, asking about their experiences participating in the project and its impact on them. It also asked them to describe in their own words the purpose of the project and their role within it, to gain a deeper understanding of their expectations and views on public engagement/co-created research.

Semi-structured interviews with researchers

Five researchers were interviewed by an independent researcher who also assisted in evaluating Parenting Science Gang. The project team selected them to represent a spectrum of activity in the project, as we wanted a range of views and experiences. A team member invited them and all agreed to be interviewed. Each interview took approximately 45 minutes and was recorded on Zoom; it was then transcribed and analysed by the interviewer. The prompt questions were about:

- Their expectations of the project
- Their role as researchers in co-designed research
- Their experiences of the project

Results

Recruitment.

We recruited just over 100 members to the Facebook group. Approximately 30 of these were researchers. The numbers were lower at the start of the project and grew as the project progressed.

Question generation and selection

In phases 2-4, the group had nine online Q&A sessions, with 14 different researchers (some researchers participated together).

The group generated 59 possible research questions, narrowed them down to a top ten and then chose their number one question:

“How does chronic depression/dysphoria differ from, say, a single episode, or discrete episodes of reactive depression? Are there markers (biological, psychological, behavioural, and current or in a person's history, e.g. trauma) that distinguish them?"

Research design

As this question was too big to be tackled in a small project, after much discussion, the group reformulated it to: "Do people report all episodes of depression to their GP? And if not, why not?"

After discussing potential methodologies, the group split the research into two main areas:

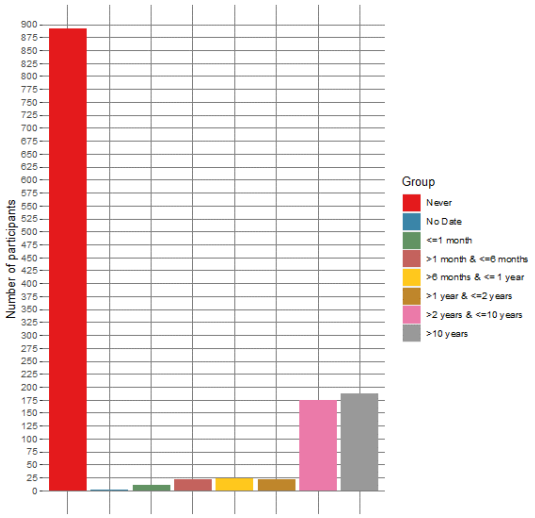
- Data science research to examine whether all episodes of depression are documented in GP records.
- Surveys and focus groups to explore experiences, reasons for visiting or avoiding the GP, and alternative sources of help.

Research results

Data Science Results

In the UK Biobank study, 500,000 participants were initially assessed, with 157,000 having completed a mental health questionnaire. Of these, 2,907 were identified as currently depressed using CIDI-SF (47) and PHQ-9 assessments (46). Among 1,342 participants consenting to share GP records, 67% had no GP-documented depression diagnosis (See Figure 4). This suggests significant underreporting of depression compared to non-depressive conditions, as only 1% lacked GP records for other issues. The findings emphasise potential gaps in GP consultations for depression.

Figure 4: Time since last GP read code referring to depression



Time since last GP read code relating to depression	n
Never	893
No date	3
<= 1 month	11
>1 month & <=6 months	23
>6 month & <=1 year	25
>1 year & <=2 years	23
>2 years & <=10 years	176
>10 years	188
Total	1342

Legend: *Firstly, we selected participants who were currently depressed at the time of completing the mental health questionnaire according to the CIDI and PHQ9 definition. The CIDI-SF (Composite International Diagnostic Interview – Short Form) measures if an individual is likely to have been depressed in their lifetime. PHQ9 looks at symptoms of*

depression in the previous 2 weeks. There were 123,040 UK Biobank participants who identified as not currently depressed and 2,907 participants who identified as currently depressed.

Secondly, we identified participants who were currently depressed (according to the mental health questionnaire) and who had consented to giving access to their GP records. 1,342 participants identified as currently depressed AND had provided access to their GP records.

Thirdly, we identified 96 read codes that related to depression [Read codes are a type of thesaurus used by GPs to code and record all relevant information arising from a patient encounter (48)*]*

Lastly, we looked at when an individual last had a GP record related to depression (one of the 96 read codes relating to depression).

Social Science Results (Focus group and survey).

The focus groups consisted of ten participants and were conducted across four Facebook discussion threads. All names have been changed.

Responses from these discussions formed the basis of a co-produced survey, which was completed by 26 people (See Additional Information 2). As it was completed anonymously, it is unclear whether the focus groups and survey participants overlapped.

Episode

The term "episodes" was a point of contention among participants. Some found that it accurately described their experience, while others disagreed. Many felt episodes had no “clear beginnings or ends” (survey comment).

When asked about recovery between episodes, 14 out of 28 respondents said they did not fully recover. For the question on episodic versus chronic depression, 16 out of 26 reported multiple episodes, and 7 indicated chronic conditions.

Several participants disliked the term ‘episodes’, arguing that this term prevented doctors from recognising it as a “chronic condition that requires ongoing treatment/medication”. As one stated, “Depression is not something that goes away if you just wait it out."

Regarding the number of episodes experienced, only one person reported a single episode, 10/21 experienced 3-6 episodes, 7 experienced 7-12, and 3 had 20-50 episodes.

Help-seeking behaviours

Most people only visited their GP (or psychiatrist/psychiatric nurse) with their most severe depression episodes. Some only went with early episodes, a few with later episodes, and some did not see a clear pattern. Only one participant sought medical help for every episode. Despair, lack of coping, or running out of self-help options often drove them to seek help. Encouragement from others was frequently needed, as approaching a GP felt daunting. Furthermore, many found it hard to speak with receptionists, feeling self-conscious and unsure of what to say. Nevertheless, with hindsight, over half (13/25) regretted not consulting a GP.

Our Focus groups identified 38 reasons for not visiting a GP. These answers were then transferred into the survey as checkboxes. The top 3 reasons people selected were:

- Didn’t think I was depressed ‘enough’ to justify going to doctor (18/28)
- I just thought what I felt was part of who I am, rather than it being an illness (15/28)
- Hoped it would pass by itself (12/28)

Most of the other reasons given fell into two main themes:

a) Feeling negative about themselves or about life. For example:

- I was ashamed about not being able to cope (11/28)
- I didn't feel any hope that anything could make it better, at the time (9/28)
- I didn't feel worthy of medical treatment and getting better (7/28)

b) Feeling negative about medical professionals or the options they could offer. For example:
   - I had negative past experience with GPs who was unhelpful (9/28)
   - The GP would not be able to give me enough time to explore what is going on and what I need (11/28)
   - I thought other options not on offer from GP would be more useful (11/28)

Participants described their experiences with GPs as mixed (13/25), with the next most common response being "a bit positive" (7/25). No one selected 'very positive'. Common complaints included feeling dismissed, rushed or not listened to. Some felt the GP was unkind or unempathetic. *"That one negative experience always stays with me, though, I am terrified of having to see someone who is similar in the future."* But people understood that some of this was related to the constraints the GP was working under. *"I do think there are some GPs who are simply prejudiced about mental illness, but I think the main problem is the overall system they work in."*

Disappointment also existed over the limited care options, with medication and short CBT courses often seen as inadequate. Often, people felt that medication, or short courses of CBT, were 'just sticking plasters' that didn't address the root causes of their distress.

"My mental health has never been looked at holistically, only ever as a set of symptoms at a specific point in time (the appointment)."

Many sought private therapy (12/24), but seeking out a good quality therapist, while depressed, was challenging. Alternative options included mindfulness/meditation, yoga and

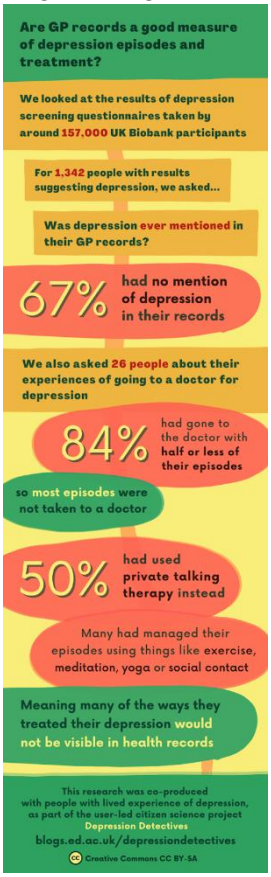
exercise, but participants wished these were either available through their GP or that support was provided to find the right help.

Key insights that the group wanted to disseminate, were transformed into infographics (see Figure 5)

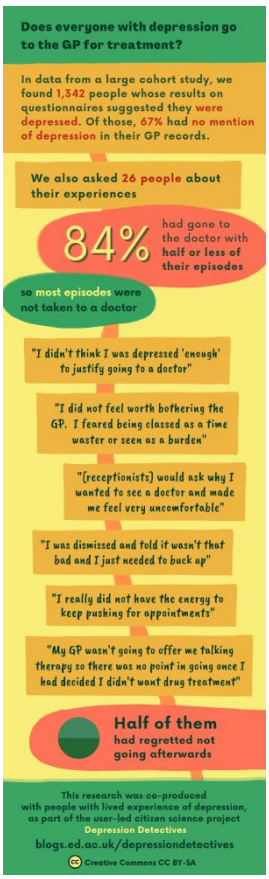
543 Figure 5: Infographics for GPs, Researchers, Policymakers and Patients, which

544 communicate the key messages the group wished to disseminate.









These results provide crucial context to the data science findings, enabling a deeper understanding of both the causes and the detailed experiences of patients. This insight is central to the project's purpose, especially for the lived experience participants.

Project Evaluation

Participant feedback survey responses

Most (10/14) did not work in a mental-health role. But most felt comfortable (7/14) or very comfortable (5/14) reading research papers or articles/books that describe scientific research.

People’s motivations for getting involved in the project fell into one of four main themes

- to learn
- to empower themselves
- to contribute to research
- to help others

Asked if the project met their expectations, most were very positive. People found it informative, memorable, and empowering.

- "The enormous wealth of knowledge on depression helped me understand the various manifestations of the illness."
- “[Researchers using their own lived experience] worked really well and helped sustain interest."
- “I found myself getting more and more excited about participating. Feeling included and contributing to a quite unique project."
- "It was quite an emotional journey at the beginning of the project."

However, some found it overwhelming and hard to keep up with.

- "I found it difficult to keep up with all the posts on Facebook. This was probably more to do with my own workload and low energy levels than the way the project was run."
- “Mostly I felt rushed and didn't have the time to do things on your time scale”

Talking directly to researchers was important for increasing knowledge.

- "The childhood trauma Q&A was really insightful. If I had not heard from those researchers, I might never have known stuff!"

A key impact of the project on participants was increased understanding of depression, in all its diversity:

- "I appreciate that labels like 'depression' can cover a huge diversity of experiences, that there is no scientific golden bullet for managing depression, that we're still figuring stuff out individually, scientifically, as a health community."
- "I realised the diversity of experiences with depression and the lack of a one-size-fits-all solution."

Other impacts included an opportunity for reflection and reducing judgment.

- "It was really interesting to be able to take some time to really think deeply about my experience of depression and the journey I have been on. I'm not sure if I realised how much work I had had to do alone and with no guidance or support, but also how far I had come and what an incredible achievement it is to finally feel like I have come out the other side and survived."
- "I think I am less judgmental of myself and others."

Though about half of the participants did not explore further, others gained skills and confidence for further study.

- "My mental health improved enormously through participating."
- "I feel better equipped and more confident to question things."

Overall, it was a positive experience that increased interest and knowledge.

- "It's been a really interesting project - thank you so much for being brave enough to think out of the box”
- "I have enjoyed the experience as it enhanced my knowledge of MH [mental health] research."

Some participants wanted more interaction with researchers and insight into their daily work.

- "I would like to have got more of a view into the day job of researchers to see how they were analysing the data and how they tried to answer our questions."

Summary of participant interview findings

The interviewer conducted semi-structured interviews with four participants via Teams, lasting about 45 minutes each. Communication issues arose due to poor internet connections for two participants. Transcriptions were anonymised and analysed for themes, with names replaced with pseudonyms: Suzanne, Frank, Sally, and Jack.

Sample and Participation Spectrum

This small sample isn't generalizable, but it revealed a spectrum of readiness for research involvement. Jack was highly motivated and engaged, while Suzanne would have preferred more guidance and structure. Frank and Sally fell in between.

Motivation for Participation

Participants joined Depression Detectives to broaden their knowledge about the research process, to manage their depression better, and to contribute or give back to others. All enjoyed the project but found some aspects challenging.

Online Platform

Facebook was considered an effective platform for reaching people while allowing a degree of anonymity. Jack noted it was particularly successful at this point in time, as the COVID-19 pandemic increased people's willingness to connect online. "I'm in lots of groups, and in other groups the interest usually just fades; it's hard to sustain it. I really think it worked in this group." (Jack)

Concerns were raised about privacy and data security, although Sally felt these issues would have been more pronounced on Zoom. Some participants expressed reservations about the overlap between the project and their personal lives, and all interviewees mentioned the need to take screen breaks for their mental health. Sally suggested using additional channels, such as WhatsApp, for important reminders.

Active Participation Experience

Participants had varied views on the co-created nature of the project. Jack praised the democratic, user-led approach and found it educational, enhancing both his motivation and critical perspective on different types of research and their limitations. "I didn't know before how to design a study and all the different factors you have to think about… and the analysis – I had not done this before, […] and it was a great opportunity to find out more." (Jack)"

Sally felt empowered by having a role in setting the agenda.

Suzanne wanted to contribute her lived experiences but was less interested in conducting research herself, often referring to it as "your research" rather than "our research." She expressed a preference for clearer guidance from researchers and felt uncertain about the project's direction. "Being user-led means that there are too many voices and no clear direction". Despite her reservations, Suzanne emphasised that she had gained a better understanding of research processes, including ethics applications.

Outcomes

All interviewed participants expressed uncertainty about the usefulness of the research outcomes. For them, "usefulness" meant making a difference for people with depression. Suzanne was particularly explicit: “There wasn't a very definite outcome… this was a bit of - not a let-down, but kind of, uhh: right, what do we do with this now?… I don’t know how the research you did will help me.” (Suzanne)

However, the project clearly impacted them personally. They realised depression's complexity. Suzanne noted her episodes varied in length, context, and cause, complicating treatment and research.

Jack also highlighted the complexity: “What was really interesting... the sort of complexity in people’s lives that might have contributed to depression… it’s not just depression, it’s two or three things at the same time…like autism or ADHD... Being in the group widened [my understanding] as people were bringing more associations and comorbidities.” (Jack)

Sally reported becoming more sceptical of generic questionnaires and RCTs, advocating for holistic, individualised and long-term research methods to capture depression properly.

“We really need to look at these things long-term and more holistically… If the goal of research is to have a healthy population, we’re not asking the right questions in the right timeframe… Depression Detectives helped to crystallise these thoughts.” (Sally)

Learning processes regarding participants’ own mental health

A significant amount of implicit learning occurred. Jack now plans to approach healthcare providers differently: “I have diabetes, and now I would always mention this to the doctor, which I didn’t do before”, “I would want a bit more time to think about different treatment options.” (Jack)

Suzanne, although often critical of the co-creation of research, enjoyed the project and appreciated sharing her opinions. It prompted her to reflect on her mental health history:

“It was thought-provoking… I realised I had several episodes of poor mental health. Actually, this wasn't just a single episode. This is something that has gone on earlier in my life as well. …..I wouldn't have sat back and examined my earlier years in such a way normally”. (Suzanne)

For Suzanne and others, the project had a quasi-therapeutic effect, offering a space to reflect more deeply on their experiences with depression and to compare these with others, helping them to construct new narratives around their mental health.

The value of sharing among peers

Participants consistently highlighted the value of sharing personal stories and hearing others' experiences. “I really liked the peer exchange and hearing what others had been through… there was a therapeutic aspect of telling one’s story - it puts it in the past… it was a privilege to hear other people’s experiences.” (Frank)

“It was good to have a place to talk about my own experience… Seeing similarities with others... Many would feel better if they just felt heard or recognised. It’s not happening through the NHS… So how do we do it for each other?” (Sally)

Jack noted that hearing researchers share their own lived experiences helped foster openness and trust:

“That actual researchers were sharing their lived experience made me feel well understood. I think it can create an environment where people probably shared a little more and with a little more comfort… it felt like a really open way to do things.” (Jack)

Although Depression Detectives was not designed as a peer support initiative, participants greatly benefited from the opportunity to share and listen in a supportive environment.

Future projects

All interviewees expressed interest in participating in future projects like Depression Detectives and said they would recommend it to others. They suggested focusing on specific themes such as depression and menopause, the impact of bullying, or underrepresented groups to deepen engagement and relevance.

Researcher feedback survey responses

Eight researchers completed the survey. Seven found the project thought-provoking, four called it good, while three described it as new, fun, and frantic. Two found it stressful. None described it as easy or exhilarating. In terms of confidence with public engagement, five felt more confident, and the others felt about the same.

Many researchers found the Q&As stressful, worrying about saying the wrong thing:
“The Q&A sessions were very frantic, and I worried about posting something in the spur of the moment, when normally putting something out in the public domain, I would try and be very careful/considered."

“I found the Q&A format quite stressful.”

“Not feeling like I was qualified enough to give an opinion. ….I was anxious about saying the wrong thing, being misleading or sharing false information.”

"At some point, the questions were unstructured and, to some extent, overwhelming."

The researchers also highlighted several benefits, including understanding the views of those with lived experience: “I enjoyed hearing the public's thoughts on our research.”

“Answering questions in the Q&A and finding out the interests of participants.”

"Really useful to get the opinions of people with lived experience over time - better than just having one or two meetings”

They also gained new insights: “Some interesting perspectives on the topic that I hadn't previously considered” and improved their communication skills “To learn how to use lay language to communicate research findings.”

In terms of explicit learning, the researchers mainly spoke about their insights into public perspectives:

“It reminded me that the public don't have a lot of detailed knowledge about how research works….might need to be explained.”

“How interfacing with healthcare, especially waiting for psychological treatment, contributes to the experience of depression.”

“I realised that there are a lot more practical questions about how to treat depression rather than what may cause depression. I think it is sensible to consider bringing more translational aspects to our research.”

Researcher interviews analysis

Five researchers were interviewed on Zoom by an independent researcher. The interviews were recorded, transcribed, and analysed by themes.

Interviewees had mixed views on using Facebook. While it was seen as an effective communication medium, appreciated for its familiarity and closed group option, concerns included distrust of Meta's ethics, privacy, and the age demographic.

Researchers valued interactions with the participants, finding them insightful and beneficial for gaining a deeper understanding of different perspectives. They appreciated the two-way discussions and that both they and the participants could ask follow-up questions.

Two out of five researchers expanded their research ideas, and two found the results more interesting than expected. One considered new research areas that could be explored, while another was surprised that the project had achieved publishable results, surpassing their expectations.

The Q&As were again described as intense, with the additional stress or anxiety about answering in written form, which other researchers could later read on a website.

All interviewees wanted the project to continue or be repeated, suggesting a longer duration to build trust. They felt the current project was too short.

Researchers cited their introverted nature as a barrier to public engagement. Furthermore, they felt that engaging the public with this complex field of research presented additional challenges due to the sensitive nature of the health data involved. Views ranged from believing public involvement in the ‘tricky bits’ was impossible, to suggesting that methods could be developed to make it possible and understandable.

The interviewer felt that there was often a misunderstanding of the term ‘co-creation’ as she carried out the researcher interviews. 2 out of 5 researchers interviewed believed lived experience members should only help with dissemination, and not be involved in the data analysis stage at all, due to the sensitivity and potential identifiable nature of the data. This reflected their differing views on public involvement in research.

Discussion

The study used a co-creation approach, where lived-experience participants played an active role in shaping and conducting the research, from choosing the topic to disseminating the results. This exemplifies respect for epistemic justice by valuing the experiential knowledge of participants alongside academic expertise, as advocated by Smith et al. (2021). Many of these participants found unexpected benefits through peer support, which helped deepen their understanding of depression. The research project itself highlighted a big gap in how often depression is recorded in GP records compared to other health issues. Participants expressed mixed feelings about the term "episodes", with some feeling their condition was more chronic. The participants also described barriers to seeking help, such as feeling they weren't "depressed enough" or having had negative experiences with GPs in the past, who seemed rushed and under-resourced. There was a strong desire for more holistic research and for more treatment options to be available via the NHS.

There are other ways to get insight into the lived experience of people who experience depression - e.g. mixed methods research using interviews, surveys, etc. But co-creation is also about changing power dynamics. You don’t know what lived experience participants really care about until you give them some power to decide, and some time and informational support to think in depth about the question. Our co-creation methodology, taking place over several months, meant that both groups (lived experience participants and researchers) could develop their understanding of each other and where they were coming from. People could go away and reflect on what they’d learned and come back with more thoughts or understanding. Lived experience participants also often mentioned how much they learned from their interactions with other participants, and the context that gave to their own experiences of depression.

Question Selection Process

We used a two-stage process to choose the research question for the group to focus on. This was a strategic decision designed to enhance participant engagement and satisfaction. In previous projects, like Nappy Science Gang, a single-stage process saw participants vote for broad questions. Which then had to be narrowed down to design a practicable experiment, resulting in disappointment for some participants. Although this provides a valuable insight into the research process, it can be disappointing for participants and lead to disengagement (*"If I had understood that we would only be answering PART of question A, then I would have chosen question B"*).

The two-stage process we used here, first developed during the Parenting Science Gang, had the group vote on a long list to choose a top ten. Then, explore those top ten questions in detail before making a final choice. This provides a space for communication about the complexity of research. The daily 'spotlight' posts enabled collaboration with researchers and facilitated communication regarding budget, time, and practical constraints. By ensuring participants understood the research limitations, we aimed to avoid post-vote regret.

As researchers and public engagement practitioners, it is our job to design processes that equalise access to information as much as possible, so that public participants can make informed decisions.

Furthermore, one of our core principles is allowing participants to choose their level of involvement. This two-stage process, with multiple entry points to ask clarifying questions or add comments, facilitated this flexibility.

Ethics and Participation

Ethical considerations presented significant challenges, mainly due to the absence of clear procedures for obtaining ethical clearance for public engagement/PPI projects. However, it

should be noted that these challenges are widespread across the sector, as noted by The Co-production Futures Inquiry (49) and consultations by the NCCPE (50) and MRC (51).

The Edinburgh Medical Research Ethics Committee (EMREC) which accepted our application, though supportive and accommodating, was not set up to consider co-created research projects where the subjects were also the experimenters. Their approach was inherently conservative and protective of our 'vulnerable' participants. Their processes were also poorly suited to a time-bound project where the question and method were unknown at the start. Having to return to the ethics board partway through introduced delays and methodological restrictions, which our participants and researchers found frustrating.

The presumption of vulnerability with regard to depression raises questions about autonomy and capacity – especially when estimates suggest up to 25% of women and 12% of men will develop depression in their lifetime (52) - and indeed 50% of the population is likely to develop a mental disorder of some description by the time they are 75 (53). Should they all be treated as vulnerable and protected from their own decisions in perpetuity?

Scottish law presumes that adults have the capacity to make decisions (54). The starting point is a presumption of capacity, and this can only be overturned where there is medical evidence stating otherwise. Furthermore, the Adults with Incapacity (Scotland) Act 2000 (55) establishes in law the principle of presuming capacity as far as possible, respecting people's choices, and using the least restrictive way to achieve the purpose. The lengthy consent process in this study seemed misaligned with its public engagement goals. A possible solution is a two-step approach, where participants first join an initial group to better understand the involvement required before committing to the whole process. This method would better align with the project's spirit. However, any adjustments to privacy protocols must be carefully considered from an ethical standpoint and may be more feasible on a platform where participants' identities are concealed.

Further, only people who were not experiencing depression were supposed to sign up to participate. However, given how many of our participants described their depression as chronic, with one episode merging into the next, it is unclear if this was a realistic request. Is it always easy to be sure one isn't currently depressed? Several participants talked about realising in retrospect that they'd had periods of depression which they hadn't recognised at the time. Further, some members described it as infantilising or patronising that they weren't trusted to make their own decision about whether it was safe for them to participate.

The intention of The University of Edinburgh to set up a specialised PPI ethics committee [Personal Communication with IB] is a promising development in addressing such challenges, and it is encouraging to see that other universities and organisations across the UK are taking similar actions (49).

Project Dynamics: Chaotic or Fun?

In general, participants were very positive about the user-led nature of the project. They found it empowering and appreciated that their voices mattered. But in the interviews, participant 'Suzanne' felt quite unsettled by feeling like she didn't know where the project was going. Whereas another felt exhilarated and excited by it. This wasn't an angle we had asked evaluation survey questions about, so we don't know how many other participants felt the same way.

The researchers, by contrast, often mentioned finding Q&As stressful and overwhelming. In a way, they were all Suzanne's. In previous projects using online Q&As (e.g. Parenting Science Gang (38), or the earlier I'm a Scientist, Get me Out of Here (56)), the hecticness was described as 'buzzing', 'exhilarating' and 'fun' by researchers. In the current project, researchers used words like 'stressful', 'anxious' and 'difficult'.

We don't know if these differences in how people felt in response to uncertainty and light chaos reflect individual personality differences, different expectations, or some other factor.

It is notable that in both Parenting Science Gang and I'm a Scientist, Get me out of Here, the researchers had individually volunteered themselves. Whereas in Depression Detectives, the department had signed up for the activity, and individual researchers had less agency about their involvement.

It will be interesting to reflect on and perhaps explore these dynamics as we design future projects. Can we predict who might find it challenging or rewarding, and can we support them to frame uncertainty positively? With major funders pressing for more co-created research (57), addressing these questions is crucial.

What We Would Do Differently?

Common feedback highlighted difficulties in selecting questions that are universally appealing. Within the Parenting Science Gang (38), groups with a narrower focus found it easier to choose a question and retained more active group members over the longer term. Participants in this Depression Detectives project also suggested that it would have been interesting to have specific subgroups, e.g. depression and autism, depression and menopause. A future project, which incorporates a range of special interest subgroups, could yield very valuable results.

Feedback from both participants and researchers highlighted feelings of being rushed and surprises due to time and logistical constraints. Some found transitions between project phases abrupt and often felt uncertain about progress or next steps. We received similar feedback on previous projects (38,40) and thought that this time we had been a lot clearer. We provided scaffolding, repeated messages, and simple timelines, but we recognise the need to enhance this further in future projects. One participant interviewee suggested a separate communication channel for key milestone reminders, such as text messages, WhatsApp, or email. We believe this "mixed methods" approach is worth exploring. We also note that this could easily have been a 2-year project, rather than a 9-month pilot.

To improve communication with researchers, we would provide concise videos and infographics that explain the co-creation concept, their role in the project, and expected time commitments. Additionally, providing the researchers with an "add notes" option before publishing Q&A transcripts on the blog may have increased their confidence that inadvertent errors could be corrected.

Several participants emphasised the importance of effectively communicating findings to influence policy and practice. However, we noticed a drop in participation during discussions about dissemination. With a longer project and more resources, we would have included more Q&As and discussions on dissemination earlier in the project, keeping it in participants' minds during decision-making. Influencing policy and practice can be challenging for academic or clinical research (58), but engaging a broad range of PPI participants could lead to more informed discussions on knowledge transfer.

Considerations

Finally, we want to emphasise how time-consuming and staff-intensive a co-created project like this can be. The relational and administrative demands are significant, especially when they take place within systems that are not designed for such work (49). Authentic collaboration with researchers, ample time, and an enthusiastic, supportive team are essential for success.

Conclusion

The Depression Detectives project successfully demonstrated a method of bringing people with lived experience and university researchers together to co-create research over an extended period of time. In ways that were accessible to a wide range of participants and had low barriers to entry. The research the group co-created highlighted the underreporting

of depression in GP records and the complex barriers individuals face when seeking medical help. Our findings underscore the need for more holistic and accessible treatment options within healthcare systems.

Participants valued the opportunity for peer support and the chance to influence research directly, finding the process informative, empowering and transformative. Researchers gained valuable insights into patient experiences, although they found the process challenging at times.

Moving forward, there is a clear need to address ethical and logistical challenges to better support participants and researchers. As co-creation becomes more prominent, understanding its dynamics will be crucial for future projects, ensuring they are both impactful and inclusive.

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Table 1: Summary of ethical issues, their relevance to the project and future implications.

Topic	**Description**	**Relevance**	**Now / Future**
Ethical Clearance	The Ethics board we submitted to was set up to review research projects and lacked	Some PPI projects have the potential to cause harm and	The Edinburgh Medical School Research Ethics Committee (EMREC) have now produced a self-

	the capacity and expertise to review PPI / co-created projects.	should be considered from an ethical angle. Many journals require evidence of ethical clearance before papers can be considered for publication.	assessment tool to help staff determine when PPI projects may need to be considered by their ethics board (59) A new cross-college PPI ethics board is currently being set up at The University of Edinburgh (personal communication with IB).
Facebook group	The activities took place within a private Facebook group that was 'discoverable', but no content could be seen until an administrator checked for a fully completed consent form.	To join most Facebook groups, you just click a link and answer a few questions. The consent form added a barrier to joining the project and is likely to have put some people off participating (particularly those with lower literacy / who are more sceptical about universities).	The feasibility of a project like this depends on participants finding and entering the private group, and then being reminded of it via their Facebook feed. However, algorithms are constantly changing, which could affect group/post visibility.

	Posts did NOT appear on participants' friends' feeds (for example).	It was important to several participants (and the ethics board) that their 'Facebook friends' did not view what was posted within DD group.	Reducing barriers to entry would potentially increase the chances of 'Facebook Friends' seeing posts.
Facebook Profile	Participants were required to have a Facebook account to participate in the project. However, we were clear within the sign-up forms that we were only looking for people with an existing account. We did not endorse people setting up a new account to take part in the project.	Some people will have been excluded from the project because they lacked a Facebook account. However, for others, this made participation in the project much easier, as it was a site they visited regularly anyway. Most people use their real name to set up a Facebook profile, so they give away their real-world identity within the group.	Other platforms could perform a similar function in future projects, but each choice comes with pros and cons.

		Our Patient information sheet and a pinned post reminded participants that they may not be fully anonymous to others when participating in the group and that Facebook may also be collecting data, based on their participation.	
Patient information sheet	Before people could join the Facebook group, they had to read and acknowledge a long Patient Information Sheet.	This was not the most appropriate format/length/style for this project.	Sector-wide conversations are ongoing around additions/alternatives to long patient information sheets.
Ethics boards are risk-averse	Our participants, by definition, had self-disclosed lived	People could only join if they did not consider	In Beange et al (2024) (60), current Wellcome-funded project (AMBER), the lived

	experience of depression, so were potentially vulnerable.	themselves currently depressed. We had to collect participants' offline contact details and ask them for an emergency contact (trusted friend or relative). We encouraged them to complete a Wellbeing and Safety Plan at the start of the project, where they could consider their own triggers and what steps they would take if they began to have difficulties. We also shared a list of sources of help	advisory group discussed safeguarding without infantilizing. They chose to have a safeguarding protocol with optional individual safeguarding plan. Sector wide discussions are ongoing around how to safeguard our lived experience participants.

		(phone numbers and websites). We had a qualified counsellor as part of the project team, and a Clinical Psychiatrist was available to discuss any concerns [this scenario never arose].	
Moving information between platforms	We moved Q&A transcripts from the closed Facebook group to the publicly accessible blog. We also summarised other discussions/information for the blog.	All names and identifying information were removed from transcripts and discussions before being uploaded or summarised for the publicly accessible blog / used in public in any way. At least 2 people checked each item	

		before it was uploaded.	
Ethics need details of the research question & method.	We had to resubmit/update the ethics part way through the project, once we had our research question and methodology.	This introduced a delay of several weeks in the middle of the project, which lived experience participants questioned. Requesting a quick turnaround by ethics meant that we were restricted to asking our survey/focus group questions to the people already in the group (limiting our numbers).	The new PPI ethics board at The University of Edinburgh will consider and create policies on how to deal with this type of co-created project in the future.

List of abbreviations

AMBER – Antidepressant Medication: Biology Exposure and Response

ADHD – Attention Deficit Hyperactivity Disorder

CBT – Cognitive Behavioural Therapy

CIDI - Composite International Diagnostic Interview

CIDI-SF - Composite International Diagnostic Interview – Short Form

DD – Depression Detectives

EMREC – Edinburgh Medical School Ethics Committee

GP – General Practitioner.

Jisc – Joint Information Systems Committee

MRC – Medical Research Council

MQ – The name of a Mental Health charity in UK

NCCPE – National Co-ordinating Centre for Public Engagement

NHS – National Health Service

NIHR – National Institute for Health and Care Research

PHQ9 – Patient Health Questionnaire 9

PPI – Patient and Public Involvement

Q&A – Question and Answer

RCT – randomised control trial

REF – Research Excellence Framework

SiP - Science is People Ltd

UK – United Kingdom

UKRI – UK Reearch and Innovation

UNESCO - The United Nations Educational, Scientific and Cultural Organization

Additional Files

Additional Information 1.pdf

The top ten research questions, as voted for by the Depression Detectives participants

Text based list

Additional Information 2.pdf

Co-produced Survey Questions and results.

Includes Patient information sheet, survey questions asked and results as graphs & copies of the open text answers.

Declarations

Ethics approval and consent to participate

Ethical oversight was secured through Edinburgh Medical School Ethics Committee (EMREC), with ethics permission reference 21-EMREC-004_SA2.

Consent for publication

Not applicable

Availability of data and materials

The co-produced survey questions and results have been included as additional information. The other datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

SC was director of the DD project and contributed to all sections of this paper.
IB was co-lead of the project and liaison to the university community, and contributed to all sections of this paper.
CK was a project co-ordinator for DD, conducted and analysed participant interviews and did most of the analysis of the group's social science research (surveys and focus groups).
SO conducted and analysed the researcher interviews.
ML accessed and analysed the UK Biobank data and prepared the table and graph.

AM was the PI of the associated research projects and led his team's involvement in the project.

The authors have read and approved the final manuscript.

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Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- AdditionalInformation1.pdf
- Additionalinformation2.pdf
- Gripp2Checklist.docx