

Title

0056

by Iona Beange in Inclusive Health Research 2024

Original Submission

Score	n/a
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1. The Entry

1 1. Lead organisation or Institution chiefly responsible for submitting this entry	Centre for Clinical Brain Sciences, University of Edinburgh
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Registered Address	Centre for Clinical Brain Sciences, University of Edinburgh Chancellor's Building , 49 Little France Crescent Edinburgh United Kingdom EH16 4SB GB 55.92147 -3.13841
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Type of Organisation	Academic/research institution
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Website URL	<a href="https://www.ed.ac.uk/clinical-brain-sciences">https://www.ed.ac.uk/clinical-brain-sciences</a>
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1.2 Chief Contact Person	Iona Beange
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Chief Contact Person's Job Title/Post	Knowledge Exchange and Impact Officer
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1.3 Name of project or programme	Depression Detectives - an online citizen science project
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1.4 Date that the project or programme began	Feb 2021
1.5 Countries in which research / implementation was undertaken	United Kingdom
1.6 About partners and collaborators	Here you should name up to three collaborating organisations and provide a contact email address for each one that you name. We will then send a request for a supporting statement, which will be taken into account in the scoring of this application.
Partner organisation/institution #1	Sophia Collins, Science is People Ltd
Type of Organisation	Other
Website URL	<a href="https://www.linkedin.com/in/sophia-collins-a4816311/?originalSubdomain=uk">https://www.linkedin.com/in/sophia-collins-a4816311/?originalSubdomain=uk</a>
Partner organisation/institution #2	Andrew McIntosh, Division of Psychiatry, University of Edinburgh
Type of Organisation	Academic/research institution
Website URL	<a href="https://www.ed.ac.uk/clinical-brain-sciences/division-of-psychiatry">https://www.ed.ac.uk/clinical-brain-sciences/division-of-psychiatry</a>
Partner organisation/institution #3	Edinburgh Neuroscience
Type of Organisation	Academic/research institution
Website URL	<a href="https://www.edinburghneuroscience.ed.ac.uk/">https://www.edinburghneuroscience.ed.ac.uk/</a>
The Case Study	
1.8 The Title of Your Case Study	Depression Detectives - User-led Citizen Science

1.9 Simple Summary	<p>Depression Detectives was a pilot, online, citizen science project that brought together people with lived experience of depression, and data science researchers. After a series of Q&amp;A sessions and discussions, the group chose the research question: “Do people report all episodes of depression to their GP? And if not, why not?”</p> <p>Within UK Biobank, 67% of people whose questionnaire answers suggested depression, had no mention of it in their GP records. Similarly, 84% of survey respondents saw a doctor with half or less of their episodes. Focus group discussions revealed many people only went to the GP with their more serious episodes or for practical help (e.g. to be signed off work). Half regretted not going afterward. 50% of our respondents used private talking therapy, exercise, meditation, yoga, social contact, etc, none of which would appear in an official record. These findings have implications for data scientists, doctors and policymakers.</p>
1.10 Introduction	<p>I was the Knowledge Exchange and Impact Officer working on an MRC Mental Health Data Pathfinder grant, alongside Professor Andrew McIntosh and his team of Big Data and Imaging researchers at The University of Edinburgh. This group were the key researchers involved in the project; taking part in Q&amp;As, discussions, data science research, etc.</p> <p>I enlisted the help of Sophia Collins, a Public Engagement Consultant who had undertaken two similar online citizen science projects before this one [Nappy Science Gang and Parenting Science Gang; funded by Wellcome Trust]. Sophia recruited two part-time facilitators - Dr Christine Kupfer, (a researcher whose interests combine social sciences, counselling and psychology) and Naomi Oppenheim (who has a background in social media moderation). As a team of 4 we designed, led and facilitated this project.</p> <p>Edinburgh Neuroscience is an interdisciplinary cross-College community at the University of Edinburgh. They helped us locate other researchers with an interest in depression. This was particularly helpful when we were recruiting topic experts for Q&amp;A sessions (e.g. social scientists with a knowledge of trauma). Edinburgh Neuroscience also helped us advertise the project, recruit public participants, and provided an opportunity for us to present to other researchers at their annual conference.</p>
1.11 Key Words	Depression, Mental Health, Citizen Science, Participatory, user-led, Patient involvement, PPI, PPIE, Data Science, Big Data, UK Biobank, GP,
Which category best fits this project or programme?	Addressing a specific unmet health need

## 2. Unmet Health Need Case Study

These will typically fall in to one of three groups: Group 1: Understanding needs and context Group 2: Designing and conducting research Group 3: Translating research into impact The various suggested sections which follow will not be equally applicable to all groups. We have given an indication of which sections may be most crucial to each but you should use your own discretion and judgement. We are seeking case studies that can be published, so please write your entry as summary, rather than a series of statements addressing the questions. You do not need to repeat information across sections. We do not expect everyone to be able to address all of the questions, as not all will be relevant.

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2.1 Who should benefit from the project or programme?  
(Applicable to groups 1, 2, & 3)

Depression is the number one cause of ill-health and disability worldwide, according to the World Health Organisation (WHO). Over 5% of adults globally are affected; that is around 300 million people (Ferrari AJ, 2013); but those are pre-pandemic figures. WHO estimates that COVID-19, directly or indirectly has contributed to an additional 53.2 million cases of depression worldwide - an increase of 28% (Kämpfen F et al, 2020).

Depression can affect anyone - of any nationality or socio-economic status. However, people who have lived through trauma and stressful life events are at increased risk.

Depression affects every aspect of a person's life - from their relationships to their ability to participate in education/work. Lost productivity alone is estimated to cost the global economy US\$1 trillion per year and is forecast to reach \$16 trillion by 2030 (The Lancet Global Health: Mental Health Matters, 2020).

Symptoms of depression include low mood and loss of pleasure/ interest in activities for long periods of time. Depression can also disrupt concentration, sleep, and appetite, amongst other things. Depression often leads to feelings of excessive guilt, low self-worth, and a sense of hopelessness about the future. This can lead to suicide.

Yet, despite substantial advances in research and demonstrations of the cost-effectiveness of medications and psychosocial interventions (Dan Chisholm et al 2016), delivery at scale and translation into real-world benefits is slow. (The Lancet Global Health: Mental Health Matters, 2020).

Although the UK Government has invested millions in mental health research over the last few years (e.g. £42.7 million by NIHR and Office for Life Sciences in 2023), The Royal College of Psychiatrists still states an urgent need for more. But what should this research be looking at? How will it translate into real-world benefits for patients? Have we asked people with depression what they think?

User-led citizen science is a way to create people-centered research that addresses the questions that matter to the participants. Depression Detectives was a pilot, user-led citizen science project which ran between Feb-Sep 2021. It brought together 70 people with lived experience of depression and 30 data science researchers as equal partners. The project took place online, within a Facebook group. Public recruitment was via Facebook adverts and posts in mental health groups, and all participants read a Patient Information Sheet/completed a survey before accessing the private group (Ethical clearance obtained via EMREC ethics board). Participants were mainly from the UK.

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## 2.2. Engagement (applicable to groups 1, 2, & 3)

The project began with a series of live, text-based Q&A sessions (1 hour x11). Topics were selected based on

- a) suggestions from the community
- b) researcher expertise
- c) the practical needs of the project (e.g. How to design research).

Through these conversations, volunteers found out more about the science of depression, and researchers heard insights from a lived experience perspective. The text-based format meant people could participate, even if they were in the midst of daily tasks. The transcripts of the Q&A sessions were then put on a public blog (researchers' names and affiliations were used, but public participants were anonymized):

<https://blogs.ed.ac.uk/depressiondetectives/online-qas-2/> )

The second phase was to design our research. The group discussed research gaps and generated >50 potential research questions! With discussion, this was reduced to 10 (<https://blogs.ed.ac.uk/depressiondetectives/2021/06/05/top-ten-research-questions/>) and after a group vote, the final question was:

"Do people report all episodes of depression to their GP? And if not, why not?"

This was investigated via:

- 1) A Data Science Project by PhD Student Melissa Lewins.
- 2) Co-designed focus group questions in our private Facebook group and an anonymous survey.

Although for ethical reasons our group members could not assist with the analysis of UK Biobank data, this part of the project did allow us to discuss things like:

- a) the 96 different codes that are available to GPs to record depression,
- b) the measures that are used (e.g. PHQ9 screening questionnaire)
- c) the questions in UK Biobank surveys (e.g. "How many periods did you have in your life lasting two or more weeks where you felt like this?". Our participants expressed how difficult it would be to provide an accurate answer, and some felt their condition was chronic, rather than episodic).

Of the 1,342 UK Biobank participants with questionnaire results that suggested depression, 67% had no mention of depression in their GP records.

Of the 26 people who answered our depression detectives survey, 84% had gone to the doctor with half or less of their episodes. 50% had used private talking therapy instead. Many had managed their episodes with things like exercise, meditation, yoga or social contact.

The focus group (10 people) gave more expansive answers on topics such as episodic vs chronic depression and help-seeking behaviour (e.g. interactions with GP receptionists and choosing only to consult a doctor with their 'worst' episodes).

Participants chose a pseudonym for reporting. The University and funder's logos were used <https://blogs.ed.ac.uk/depressiondetectives/wp-content/uploads/sites/4392/2021/12/Depression-Detectives-Results-of-survey-and-focus-groups-1.pdf>]

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2.3. The Research  
(Particularly relevant  
for groups 2 & 3)

Our key finding is that most episodes of depression are NOT taken to a doctor.

As this has implications for a variety of stakeholders, we produced and distributed 4 targeted infographics  
(<https://blogs.ed.ac.uk/depressiondetectives/2022/01/07/infographics/>)

For data scientists, our results indicate that electronic health records (eHR) may provide an incomplete picture of depression. Many of the ways that people deal with depression (e.g. private talking therapy, meditation, exercise, etc) will never appear in official records. For researchers using eHR or prescription records as a way to estimate the 'number of episodes' of depression a person has experienced, our results have highlighted some additional limitations.

Within our research group [Professor Andrew McIntosh's group, Division of Psychiatry, University of Edinburgh], the results of this citizen science project have led to several in-depth discussions, including a recurring conversation on the differences between 'episodic' and 'chronic' depression. They have appeared in a PhD student thesis (Melissa Lewins) and influenced several grant applications (see below).

To disseminate the project locally, several presentations were made at our departmental journal club, both during and after the project. Wider dissemination to researchers was achieved through formal presentations to organisations such as MQ (Mental Health Research) and PGC (Psychiatric Genomics Consortium). Informal discussions have also been held with research cohorts including Generation Scotland, UK Biobank and Generation Malawi.

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#### 2.4. Translating to Impact (Particularly relevant to group 3)

For medical professionals, our results highlighted reasons why people did not go to their GP. These included how 'bad' they thought their depression was at the time and their past experiences of receptionists and doctors. Several people mentioned the dominance of drug treatment, and that they would like to be offered counselling. However, it is important to note that half of our respondents regretted not seeking help afterward. So small actions could make a difference (for example, one participant suggested a 'mental health' button within automated telephone services). These results have been distributed via GP networks and social media.

For policymakers, our results highlight the need for additional funding and service provision (beyond drug treatments). People requested longer appointments for mental health conditions and the ability to consult with the same doctor every time. This has been communicated via direct correspondence with MSPs and the Health and Sport Committee at the Scottish Parliament.

We also created an infographic for patients, which communicated the project results. This was disseminated via the Facebook groups we used for recruitment originally and other social media channels, particularly during Mental Health Awareness Week / World Mental Health day.

Finally, we have disseminated the practicalities of our project to other Patient and Public Involvement and Engagement (PPIE) Professionals both within our institution and nationally via ScotPen (The Scottish Public Engagement Network) and The NCCPE (The National Co-ordinating Centre for Public Engagement).

By creating infographics targeted at each of these different audiences, we were able to garner attention in a way that may not have been possible with more generalised outputs. The infographics, social media posts and word-of-mouth recommendations led to several invitations to speak and allowed us to disseminate the project and its findings to a range of different audiences.

We also captured some of the impacts the project had on the individuals who took part.

Public participants felt more motivated to read research literature after the project; and more confident to critique it / recognise its limitations. Some also mentioned that they would approach their healthcare provider differently. All stated they would take part in similar projects again.

Researchers remarked on the benefits of engaging over a longer period of time (vs one-off events) and reported an increase in confidence engaging with patients. Comments included "insightful directions for future research", and that they will "consider bringing more translational aspects to our research"

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## 2.5. The Future (Applicable to groups 1, 2, & 3.)

The learnings from this pilot project will be taken forward in many ways - not least in the awareness and understanding of the value of lived experience inputs by the researchers who participated.

Our ultimate goal is to embed lived experience within our future research grants - a process that we have already begun.

Of particular note is our new £4.5 million Wellcome Trust funded AMBER project (Antidepressant Medications: Biology, Exposure & Response). The scientific focus of this grant is genetics/genomics, data science and cellular methods, but it also includes an ambitious Patient and Public Involvement (PPI) programme. These plans include a Lived Experience Advisory Panel (LEAP), several participatory research projects, and a program of knowledge exchange /science communication activities (to be decided upon and co-produced by the LEAP).

Depression Detectives members were consulted ahead of the AMBER application and helped shape its structure and focus. This initial consultation produced a mixture of responses to the idea of genetic testing to inform antidepressant prescribing from “I would be first in the queue” to “I think it’s way too medication centric” and “I certainly wouldn’t give permission to sequence my whole genome”. This led one Depression Detectives member to suggest that we should produce “...an easy-to-access explanation of genetic tests, what they involve and what benefit/risk they could bring”. So this was also included within the application/plans.

Another topic that came across clearly in our discussions was the importance of considering medication in the ‘real world’ context: “I like it [personalised medicine] as part of a holistic treatment – but they never normally look at what else is going on”. As a direct result of this feedback we included a piece of work looking at the clinical experiences of people with difficult-to-treat depression. What is it really like to have had a fruitless experience of medications to date? And how might we engage these patients with the future developments that may ensue from this programme of research? We aim to achieve this through a series of peer interviews and the facilitated creation of digital stories.

Within AMBER, our aim is to achieve integration between lived experience and our scientific workpackages. In an effort to achieve this our LEAP will take on ‘focus roles’ and receive training linked to specific elements of the programme (eg. Data science, genomics and cell lines), so that they can participate in discussions alongside researchers.

[[https://www.kcl.ac.uk/research/amber-antidepressant-medications-biology-exposure-response#:~:text=The%20AMBER%20study%20\(Antidepressant%20Medications,response%20\(2023%2D2028\]](https://www.kcl.ac.uk/research/amber-antidepressant-medications-biology-exposure-response#:~:text=The%20AMBER%20study%20(Antidepressant%20Medications,response%20(2023%2D2028))].

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4. The Prize Fund	<p>The prize fund would be used to employ a part-time person who would manage our online lived experience group. They would act as a 'go-between' for researchers and the public members. They would build on our existing community, recruiting and welcoming in new members. They would work across several of our depression research projects, translating our research questions, applications, findings etc into interactive posts and regular online events that our lived experience members could meaningfully engage with. They would also act as moderator, ensuring we maintain a safe and respectful online space, where people feel able to participate.</p>
5. Your advice to others	<p>This type of engagement project is highly rewarding and can achieve significant insights and benefits for both public participants and researchers. However, it is very time-consuming - 8 months was not really enough time for the full process (recommend 12-18 months). People form relationships with people - so good facilitators are vital. Their time, energy, enthusiasm, patience and understanding are the make or break of these projects. This project had 4 part-time facilitators and often felt like it could use more.</p> <p>And a practical note: you can never repeat the instructions too often. Not everyone will see/read every post.</p>
6. Supporting Evidence	
6.1. Funders	<p>This activity took place within 2 research grants:  MRC Mental Health Data Pathfinder award (MC_PC_17209) and The University of Edinburgh, Leveraging routinely collected and linked research data to study the causes and consequences of common mental disorders, Mar 18 - Dec 20, £1,272,880, <a href="https://mhdss.ac.uk/">https://mhdss.ac.uk/</a></p> <p>European Union's Horizon 2020 research and innovation programme, CoMorMent - Investigating comorbid mental ill-health &amp; cardiovascular disease (Grant agreement No. 847776), Jan 20 - Dec 2024, €5 998 613,75, <a href="https://www.comorment.uio.no/">https://www.comorment.uio.no/</a></p>
6. 2. Academic/Professional Publications	<p>This work has not been published in a journal, but we are open to doing so.</p> <p>Edinburgh Open Research [Conference], 26-Jul-2022, Depression Detectives (Citizen Science)[Poster and video], Beange, I. and Collins, S. DOI: <a href="https://doi.org/10.2218/eorc.2022.7114">https://doi.org/10.2218/eorc.2022.7114</a></p>
6.3. Other publications	<p>Depression Detectives Blog on the University of Edinburgh blog site.</p> <p>Q&amp;A transcripts: <a href="https://blogs.ed.ac.uk/depressiondetectives/online-qas-2/">https://blogs.ed.ac.uk/depressiondetectives/online-qas-2/</a>  Blog posts charting progress (including top 10 potential research questions): <a href="https://blogs.ed.ac.uk/depressiondetectives/category/news/">https://blogs.ed.ac.uk/depressiondetectives/category/news/</a>  Results including Survey and Focus Group Analysis and infographics: <a href="https://blogs.ed.ac.uk/depressiondetectives/our-results/">https://blogs.ed.ac.uk/depressiondetectives/our-results/</a>  Published online between Feb-Sep 2021.</p>