ScotPEN Wellcome Engagement Award

Reporting Template

This form, including relevant appendices, must be submitted electronically as a single PDF file upon completion of your project and in any case **no later than 8 weeks from the end date**.
Please send to: scotpen-wellcome-engagement-award@glasgow.ac.uk

Please note, this information will be shared with external evaluation consultants who have been commissioned by SWEA and Wellcome, and will be used for the purposes of evaluating this grants scheme. The data gathered is extremely valuable in understanding the value, outcomes and impacts of this scheme as a whole; what improvements need to be made; and will help to inform how Wellcome PE Enrichment grants are supported and awarded in the future.

Adapted from *Enriching Engagement* scheme, University of Oxford

[redacted]

1. Project Information

Project lead: Name and position	Professor Andrew McIntosh, Chair of Biological Psychiatry
Project title	My depression, your depression – same name different stories
Start date	1st Feb 2020
End date	30 Jun 2021
Total funding awarded	**£65,600**

Project summary

Please refer to the summary originally provided in your application and modify it if appropriate. (Summary for external publication; maximum 250 words).

This project aimed to raise depression up the political and social agenda in Scotland using the voices of people who live with it.

We collaborated with people who had lived experience of depression to create digital stories. Each person who participated had full editorial control over their video, so they could tell their own story their own way. Three public groups participated with us – Adults with lived experience of depression, parents of teens with mental illness (in partnership with the charity Parenting Mental Health) and young people who talk about their own mental health experiences (in partnership with The Princes Trust).

Researchers who usually view depression through the prism of data formed the fourth group. They were supported to create their own digital stories about an aspect of their research.

By the end of the process, our participants felt more empowered to speak out about mental health, our researchers had improved engagement skills. We as a research group had also formed new partnerships.

The videos have been brought together on the Patient Voices website (https://www.patientvoices.org.uk/mydepyourdep.htm) and have been used as the basis of online talks and events (to both academic and public audiences). Together they highlight the ubiquitous nature of depression.

Moving forward, these videos will continue to be a major ongoing resource that we will use both online and in-person, at community, parliamentary and academic events.

2. Inputs

What resources were used in the development and delivery of the project?
For example: funding including any additional/partnership funding; in-kind support; key staff involved; partners – internal or external; training/support received.

- **Dr Iona Beange, Knowledge Exchange and Impact Officer at University of Edinburgh**
  She was the Manager of this grant/programme of activities. She is paid from European Union's Horizon 2020 research and innovation programme under grant agreement No. 847776.

- **PhD Intern (paid) Anders Jespersen**
  Anders was employed 6 hours a week via the Employ.ed scheme at the University of Edinburgh. He assisted with recruitment and events, as well as creating his own digital story. His assistance was invaluable.

- **Paid project partner – Patient Voices.**
  Major project partner. They ran the workshops and helped people to produce their digital stories.
  They allowed Iona Beange to take part in their COVID-19 set of workshops free of charge, so that she could have first-hand experience of the digital story creation process.
  They also assisted at dissemination events and presentations and in a multitude of other small but important ways.

- **Paid project partner Real Talk**
  Assisted with recruitment and online dissemination events (advised on online event design and acted as compere for delivery).

- **In-Kind project partner – The Princes Trust**.
  Our online digital storytelling workshops became part of their 'Team' training programme for young people aged 16-25 who are unemployed and looking for something new.

- **In-Kind project partner – Parenting Mental Health**
  A charity which provide hope and support to parents of young people with mental illness. They helped recruit parents for the digital storytelling process and are co-producing dissemination events etc with us.

- **In-Kind project partner – YouthLink Scotland**
  National Agency for Youth Work in Scotland who have links to youth workers and projects across Scotland and helped put us in touch with The Princes Trust.
- **The researchers** involved in creating the digital stories were funded from a variety of different sources including Wellcome Trust, MRC and Mental Health Research UK. Several other researchers helped with

- **Edinburgh Neuroscience (at University of Edinburgh)**
  Hosted our project on their website.

- **In-Kind – BNA**
  Hosted us for an online public event as part of their online ‘Bring your own brain’ festival. Assisted in planning, running and advertising the event.

- **In-Kind, UoE - Jisc Surveys**
  Available to University of Edinburgh staff free of charge. Used for recruitment forms and evaluation forms.

- **In kind, UoE – Zoom**
  Our information events and online events took part on the UoE institutional zoom licence.

- **Project image** designed by MSc student on placement Enyue Yang (MSc Science Communication and Public Engagement, UoE)
  And modified by Anders Jespersen.

3. Outputs

(i) **Audiences and partners.** What individuals/ public groups were involved? (e.g. young people; adults; families; schools; community groups; local residents; patient groups etc.). Please also include any demographic data collected (e.g. age; gender etc.).

- **1 x Project Manager – KE officer** (female)
- **1 x PhD Intern** (male)

- **5 University of Edinburgh researchers created digital stories** – 3 PhD students (1 male, 2 female) and 2 post-docs (1 male, 1 female)

- **4 adults with lived experience of depression created digital stories.** (3 female, 1 male).

- **6 parents of young people with mental illness created digital stories** (all female)
  Parenting Mental Health has a female founder/director whom we are collaborating with.

- **Princes Trust** – 1st set of digital stories workshops
  11 young people (5 male, 6 female; 2x16yrs, 3x17yrs, 3x19yrs, 1x20yrs, 1x22yrs).
  We started working with them a few weeks into their 6 week training schedule and unfortunately they did not produce any final stories. However, they did benefit from the digital storytelling workshop process.~

  We intend to work with another group of Princes Trust 16-25 year olds in the Autumn 2021 in a longer 12 week process, and hope that some of them will complete their digital stories in this longer timescale, that is planned further in advance.

- **Patient Voices** (1 male director, 1 female director)
- **Real Talk** (1 female director)

Events:

- 4 Dec 2020 – **MQ Data Science Meeting** – mentioned project as one example in a talk about Public Engagement and showed Cary's digital story (online: ~50 attendees, mostly data science researchers).

- 20 Jan 2021 - **Presented researcher's digital stories to other researchers**. (online: ~12 attendees).

- 22nd April 2021 – **Presented digital stories to Public Engagement professionals at UoE** (online: ~30 attendees)

- **22nd April – presented digital stories to public at BNA event** (online: 61 attendees).
  32 people took part in our Mentimeter. Of those:
  (people were able to give more than one answer)
  - 15 had lived experience of depression
- 14 had a family member or close friend who has/had depression
- 15 have an interest in depression
- 12 were researchers
- 5 were storytellers / had an interest in storytelling
- 2 were public engagement professionals
- 20 thought the event looked interesting, so came along.

- **12 May 2021 – Presented adults with lived experience digital stories to researchers at a special lecture** (online: 17 attendees).
  13 people took part in Mentimeter. Of those:
  (people were able to give more than one answer)
  - 6 were researchers
- 4 were students
- 4 had lived experience of depression
- 6 had a family member or close friend who has/had depression
- 8 have an interest in depression
- 1 was a Public engagement professional
- 1 was a storyteller / had an interest in storytelling

(ii) **Activities.** Please indicate the types and numbers of activities or events delivered and/ or resources produced (e.g. festival; exhibition; workshop; walking tour; video; publication; online resource).

Digital Stories – 9 digital stories are currently on the Patient Voices website. 6 more are in progress and we hope to produce another set when the young people from The Princes Trust work on theirs in the autumn.
https://www.patientvoices.org.uk/mydepyourdep.htm

The Patient Voices website receives around 4 million hits per year and gives wide visibility to the digital stories, especially within the NHS and academic institutions around the world.
All released digital stories are available for educational use under a Creative Commons Attribution-NonCommercial-NoDerivs 2.5 License.

Walking Tour – The 9 digital stories were turned into a walking tour that was advertised as part of Edinburgh Science Festival
https://arcg.is/0rW4jm

Online Events (see details above).

- 4 Dec 2020 – MQ Data Science Meeting – mentioned project as one example in a talk about Public Engagement and showed Cary's digital story afterwards.
- 20 Jan 2021 - Presented researcher's digital stories to other researchers.
- 22nd April 2021 – Presented digital stories to Public Engagement professionals at UoE
- 22nd April – presented digital stories to public at BNA event
- 12 May 2021 – Presented adults with lived experience digital stories to researchers at a special lecture.

Events in immediate future

- *Event planned as part of Explorathon (Sep 2021) which will showcase 2 or 3 of the parents stories and 2 of the researcher stories (the ones which talk about teenage mental health).*

- *Descriptions and links have been submitted to Glasgow, Orkney and Midlothian Science Festivals for inclusion in their 2021 online science festival programmes.*

Exhibition – Exhibition materials have been purchased for a touring community exhibition (large banner, ipads and stands, leaflets, posters etc). These will be used to create in-person exhibitions as soon as the COVID-19 rules allow exhibition planning to take place.

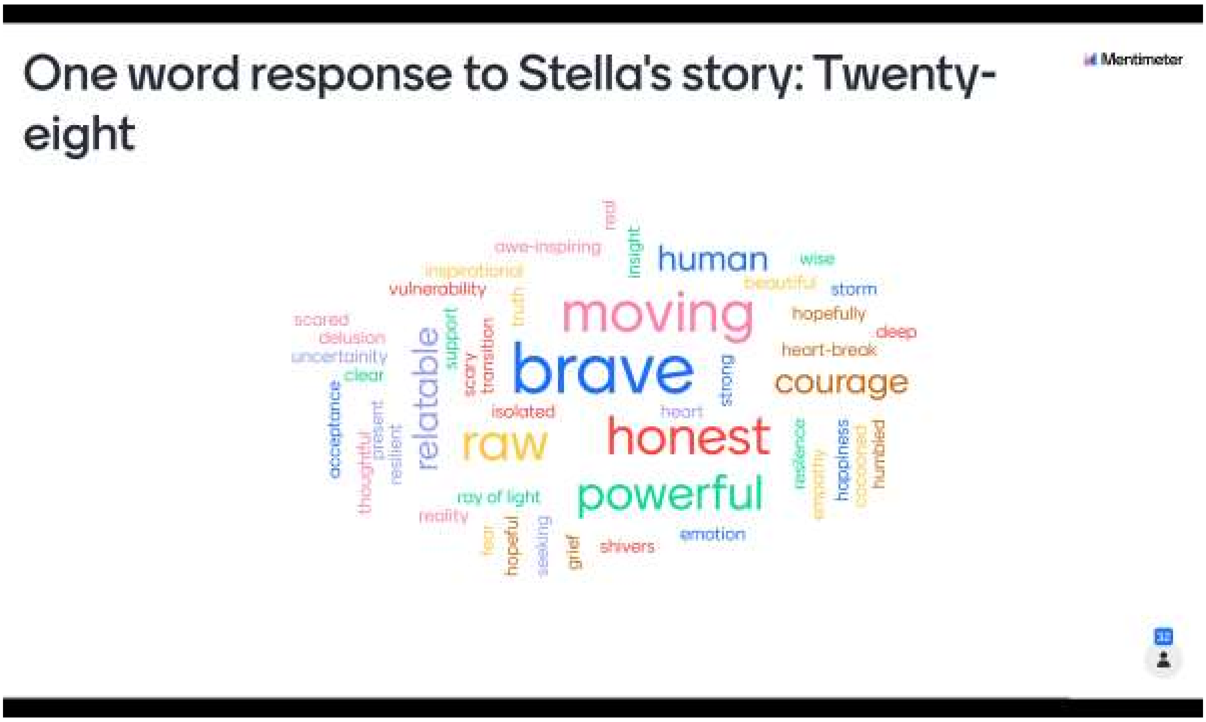
We will also continue within online and/or blended events.

4. Evaluation

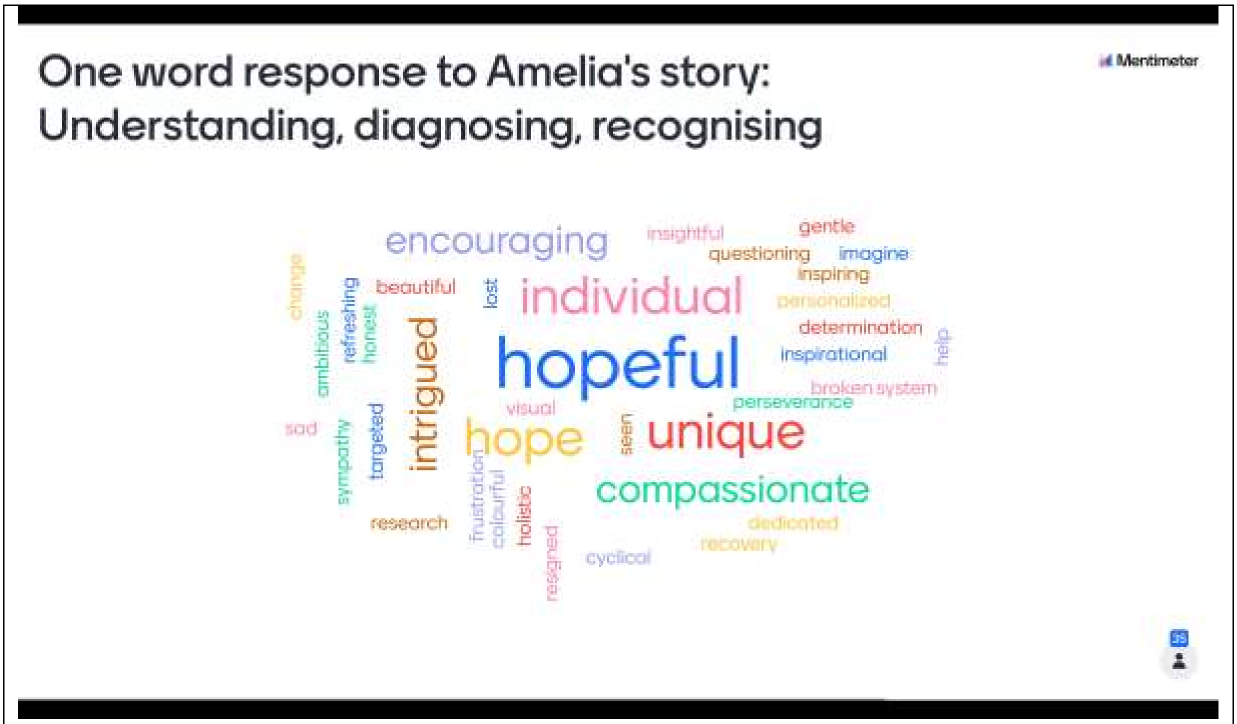
What evaluation method(s) did you use to gather evidence and indicators of outcomes and impacts?

Online surveys were used to gather data from storytellers before and after the digital story creation process.

Mentimeter was used to collect data during events – multiple choice questions to collect some audience data, and then word-clouds to collect responses to the digital stories they had just watched. This acted as a pause for reflection between videos as well as a way to collect some evaluation data. The word cloud slowly evolved 'live' on the screen which was quite soothing and a very positive experience for the storyteller whose video had just been shown.
See below for an example from Stella (adult with lived experience) and Amelia (PhD student). Once we have more of these we can start to do some comparative analysis.



One word response to Stella's story: Twenty-eight


One word response to Amelia's story: Understanding, diagnosing, recognising

We also took a note of the total number of attendees and kept a copy of the questions that were asked during events. These help prepare our speakers for the next event and show us more generally what our audience are interested in (which may be useful for future PE efforts).

Example of questions. The first 2 were directed towards adults with lived experience and the second 2 towards researchers.

1. “To Stella and Karen - did you find it in some way therapeutic creating these digital stories?”
2. Now that you've taken part in this project to you feel better equipped to share your depression story & experience with friends & family who you wouldn't normally have?
3. “Cancer has been dissected and categorised into dozens or even hundreds of different buckets. How many different "buckets" do we have for depression and other mental illnesses and how confident are we in understanding these buckets
4. For the researchers - Do you feel that your research has potential to identify people who may be more predisposed to getting depression?

Postcard to self – at the end of the online events, people were invited to complete an online form with a short message they would like sent to them in approx. ~1 months time to remind them what they were thinking at the end of this event. We asked permission to use this for evaluation purposes and asked a few other evaluation questions on the form. (Including option to sign up to our mailing list) (6 people completed this after BNA event, 1 person after special lecture and 1 person after the walking tour).

Examples of what people wrote for their postcard:

“I want to remember that things get better from here. I also want to represent my life and experiences creatively.”

“Remember that you would not be where you are today with the experiences you have lived, both good and bad.”

“Think of others' mental health, and take a moment every week to think about your own too.”

“Remember to not get lost in the data, remember the uniqueness of every individual.”

Demographics from postcard forms (8 people)
7 people in UK, 1 person in Turkey
Age: 6x 21-35, 1x36-45, 1x46-55
4 had personally experienced mental ill-health.

Reflective blog: Anders Jespersen wrote a reflective blog piece at the end of his PhD internship. Patient Voices staff and Iona Beange will be asked to do the same after the last workshop (winter 2021).

5. Outcomes/Impact

What happened as a result of the project? How many people did you reach/engage? Please refer to the intended outcomes provided in your Application. Please highlight whether these outcomes occurred, and any other outcomes, as may be appropriate.

(i) **Public.** Number reached/engaged; key outcomes.

Outcome from application:
For people with lived experience of depression:

1. To empower them to tell their story and make it known to others
2. Personal growth and the confidence to speak out about their experience again in the future.

Public who created digital stories – 10
+ 11 young people who gained skills and experiences from the digital story creation workshop process, but who did not manage to complete / release their stories.

For the 4 people that have finished their digital stories, comparative evaluation (start vs end) demonstrated that by the end of the process, the participants felt more confident about storytelling, video editing, audio recording/editing, selecting appropriate images for a project and speaking in public about their mental health.

The purpose for their stories included:
“Sharing my experience might make someone else in a similar situation feel less alone.”

“I hope people will find themselves in my story and not feel as alone and to feel validated in their feelings”

“Raise awareness about the impact of a long hospital stay on patient mental health.”

“To help reduce stigma of postnatal depression and to show that it is possible to fully recover”

Text comments in the post-workshop evaluation included:

“ …..a big thank you. It’s been a real pleasure to participate in this process and one I’d heartily recommend to others.”

“I can be proud of my lived experience of depression - in that my journey has given me insight into the condition that others may find interesting (e.g., researchers, people with a family member with depression).”

Next steps

“I am now going to be working on a project in a university Student Services setting getting students to share lived experience audio recordings with animated images (on various topics including living with a mental or physical health disability).”

“I’m hoping to start a peer support group in my town”

Evaluation from storytellers who showed their stories and answered questions at events:

Storytellers felt welcome, acknowledged and heard (all 5/5), and safe (4 or 5/5) All said they would be willing to take part in future events.

Text responses included:
“The word cloud response was such a good idea! Thought that worked really well.”

“I think having the project introduction from Iona first was great - to put things into context. It was also exciting to hear about future potential uses for the digital stories and ongoing projects that people in the audience could sign up for.”

“I thought Lily did a really good job of guiding us through the videos (e.g., making space for reflecting/having a breathing break). She also ran the Q&A really effectively, too, I thought.”

Attendees at public event in association with BNA – 61

Outcome from application:
For public audience:

3. Increased understanding of what depression looks like and that it can affect anyone.
4. More positive attitude towards people with depression and other mental health conditions.

Anders – Intern “Thank you all SO much! I did not want to leave that call, it was just such a great, safe and enlightening space.”

Alex Campbell, BNA Head of Marketing and Communications: “I enjoyed it so much - thank you so much for running this event. It was wonderful.”

Public Comments in Chat:

- Transformational insightful reflective moving
- Your videos will help lots of people
- I really admire the story tellers have been moved to tears. It has been helpful to hear their stories.
- Thank you all story tellers very moving and powerful

(ii) **Research/Researchers.** Number reached/engaged; key outcomes.

Outcome from application:

For Early career researchers / PhD students

1. An opportunity to learn from patients and gain insights that could contribute to their research / set a new research direction.
2. PE skills / practice

5 researchers created digital stories

Comparative evaluation demonstrated that by the end of the process, the researchers felt more confident about storytelling, video editing, audio recording/editing, selecting appropriate images for a project and speaking to the public about their research.

Researchers particularly enjoyed that "the sessions had a really positive and encouraging atmosphere" and "The challenge of thinking about our research from a different perspective."

"Family and friends understand what I do better now. It's nice to have something to be able to show people in the future that might be interested in what we do."

"I think time deliberately set aside for this is key. I really enjoyed it but , even if I had access to the software, I might not do this again because the time commitment was high. It would need to be part of a scheme, written into a grant or at the direct request from someone senior - Effectively giving permission." (PhD student).

"The process was completely different to my day job and it came as a surprise. eg. opening sessions with just a gentle chat. It felt very creative."

PE PhD internship

Anders Jespersen was employed for 6 hours per week for 1 year, to assist with the project.

- He took on a variety of tasks including image editing (project image), creating social media and website content, writing recruitment text & creating recruitment videos.
- He represented the project to various external charities and third sector organisations as part of our recruitment efforts.
- He acted as main point of contact with Patient Voices for researcher and adults workshops.
- He created his own digital story about his research and persuaded other researches to take part in the process.
- Participated and offered ideas during discussion about how to move the project online.
- Suggested BNA as a partner and took the lead on liaisons with BNA for event planning.
  Led presentations at Special Lecture and UoE CMVM PE forum.
  Developed an understanding of university processes and procedures.
- Collated and recorded information and evaluation data.

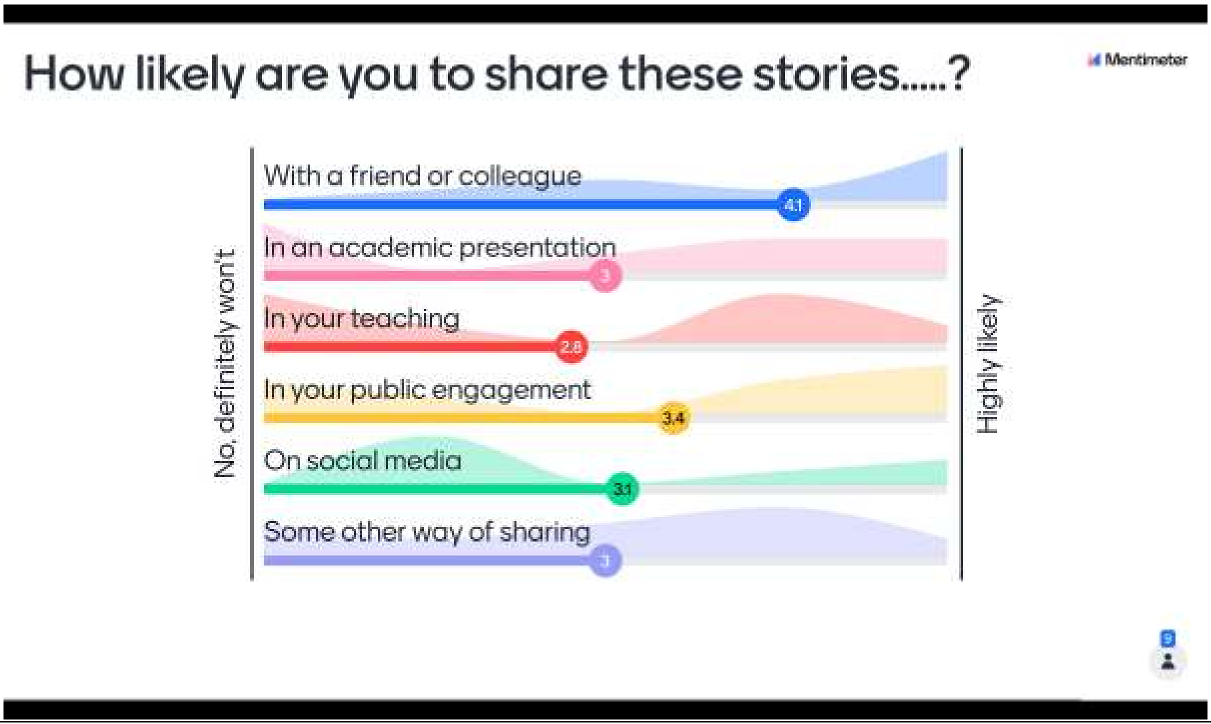
Anders is now applying for Post-doc positions and recently applied for a Schmidt Science Fellowship. His proposed project for this fellowship contained a PE / Citizen science section.

79 researchers have attended events where some of the digital stories were presented.

At the end of the special lecture, we asked the researchers to think about the stories in the context of their own research. Their feedback included:

- Useful in engagement work and in work with funders etc
- My work involves mental health data, so this session has given me food for thought as to how we talk about this aspect in our own plans
- Very clear and effective way to deliver a lot of information in a short but powerful way, that will help with teaching. I may want to try and use this medium for future work.
- Would be great to have this for dementia as personal stories can be so important here too.

We also asked the researchers to rank the following items on a scale of 1-5.



How likely are you to share these stories.....?

(iii) **Other outcomes:** e.g. for partners, institution or unexpected.

Patient Voices – COVID-19 has meant that their 3 day in-person workshop has had to transform into a 6 week online processes (1x2hour workshop per week)
This has had advantages including:

- Wider geographic spread of participants
- Easier for people with caring responsibilities to attend (which was particularly important for our group of parents).
- Additional time for participants to think about and reflect on their story, perhaps discussing it with others.
- More time for participants to find or create the images they will use. This has allowed some participants to produce their own artworks, which wouldn't have been possible during an intensive weekend process.

The disadvantages are obviously talking about a highly emotional subject online, without others physically present. It was harder for the facilitator (one of whom is a trained counsellor) to just take someone aside and interact with them one-on-one (although we did have break out rooms available and some people did choose to interact with Pip online at times separate to the workshops)

Going forward, they intend to continue to offer both models – online and offline and are considering how a blended approach might work.

PE Ethics at University of Edinburgh
The main part of this project was approved by the ethics board in Clinical Psychology. The evaluation part was approved by the ethics board in The College of Medicine and Veterinary Medicine, as a separate application. However, neither of these were set up to receive or assess PE applications.

Thus, this application kick-started discussions at a high level within the university of Edinburgh to consider how and where public engagement ethics should be dealt with.

Progress so far: PE and KE will be explicitly mentioned in the first University Research Ethics Policy and embedded into the new portal that all staff will use for ethics applications. Resources have been budgeted for to make sure the system is fit for purpose with regards to PE. The timing of all of this has been delayed by COVID-19, but progress is being made.

Real Talk – Real Talk was based around in-person mental health storytelling events. Due to COVID-19, all of their activities had to move online. We shared and discussed this process together, so that both our events and Real Talk's events would benefit from our collective thoughts and experiences.

Online Discussion Events – compared to in-person events these are widening our audience reach both geographically and to people who may have caring responsibilities etc, which would make attending in person events difficult.
As we move forward we will continue to do a combination of in-person and online events with the digital stories, and consider how a blended approach might work.

The online events are also helping direct people towards the other digital stories (educational materials) on the Patient Voices website

PhD Internships via Employ.ed
Employing a PhD intern for PE is something some PE colleagues at University of Edinburgh had considered but weren't sure how to do.
By taking the lead in this project, it demonstrated that it was feasible and Anders and I were able to answer questions about the benefits and challenges. Several PE staff mentioned that they will consider writing funds for PhD Intern into their future grants.

Parliamentary / Government Engagement.
Outcome from application:
For policymakers:

- To hear directly from the public about their experiences and priorities
- To hear the results of the research and how it can feed into policy.
- An increased understanding of the practical issues that are holding back depression research and what might be possible if these were removed.

It has not been possible to do much engagement with MSPs / cross-party groups during this time due to the focus on COVID-19. The parliament building has been closed, so an exhibition was not possible.

However, we did make efforts to make MSPs and the cross party group aware of the project and the resulting videos, and hope to complete this outcome once it is feasible to do so. (There is currently a huge back-log of potential exhibitions in the parliament building, but we are on the waiting list. We are also considering other ways to achieve the same objective).

However, our continued engagement with the Cross Party Group did enable us to submit some written evidence to them, which was included in the Data and Measurement section of their review, which has been presented to the Scottish Government, to inform their updates to the Mental Health Strategy 2017-2027.
"Priorities for Data and Measurement
1. Ensure researchers are included in the design and implementation of data measurement processes for mental health and, where possible, improve access to data for researchers."

Similarly, we were able to submit a response to the Digital Strategy for Scotland Consultation, the report from which lists us as a contributor and Point 67 of the report states: "*Small numbers of respondents required a better definition within the strategy (e.g. NHS systems used by health visitors and nurses to include data science researchers)*;"
The final report includes statements such as:
"Stimulate innovation through innovative procurement and the availability of nonpersonalised research data."

These points are related to several of the researchers stories – particularly Cary’s one which asks people if they are willing to share their health data with researchers.

So continuing to engage with these groups and make them aware of what our priorities are has enabled us to make contributions, even across this tricky time.

6. Legacy

Did this project generate long-lasting resources or partnerships and/or lead to additional PE or research projects being developed?

Although this project has officially ended, due to COVID-19 and indeed to the nature of the project, it is very much ‘ongoing’ and although I have provided some initial impacts here, I believe the most impactful things are still to come (e.g. it has not been possible to do anything with policymakers, but I hope that this will change as they get back to considering things other than COVID-19. Similarly, we have held very few events – and the exhibition materials although received are as yet unused).

I am happy to stay in touch with your evaluators and to fill in additional forms/update this form in Jan 2022 when the digital story creation workshops are finished and we are able to plan/undertake more events.

I’d also be happy to speak to them again at a later time-point should that be helpful (I’m not sure of your timescales).

The long lasting resources are

a) The digital stories themselves – which can be used by us and other researchers / charities / organisations.

b) The Exhibition materials so we can present this project as an in-person exhibition at science festivals, community centres, conferences, science centres, librarires etc.
The formats that have been ordered can also be ‘reskinned’ (magnetic attachments) for other uses too, making them real legacy pieces which will be used repeatedly for our public engagement efforts well into the future.

c) Ipads + stands – As well as being pride of place in the My Depression, your depression exhibition, these can also be used to present our 2 other activities: Risk and Resilience game and Dr Data Card swiping game (which is about to be updated to a newer format).

Partnerships

We intend to keep the partnerships established during this project alive and indeed several follow on opportunities have already arisen.

- One of our researchers has followed up with YouthLink Scotland and used that conversation as the basis of her PE section in a new Wellcome Trust grant application.
- We intend to write a journal paper in conjunction with Patient Voices and to present this project at upcoming conferences.
- There are plans to stay involved with Real Talk, especially once they are allowed in-person events again.
- The partnership with The Princes Trust is highly valuable, and gives us a safe way to interact with a group of vulnerable young people, that we would otherwise find it hard to engage. We are currently looking to develop new offerings that will form part of their youth training courses in the future.
- The partnership with Parenting Mental Health is highly relevant to several of our researchers who are working on teenage mental health. We are looking at ways to both use the stories and develop new grants in partnership with them in the future.
- The researchers are continuing to find ways to use their stories both as part of their engagement efforts and during academic conferences etc.
- This project has helped us re-establish connections internally at the University of Edinburgh with other public engagement professionals and with Edinburgh Neuroscience etc.
- The BNA meeting takes place every 2 years, so we will be looking at how we can get involved again with that when it next occurs.

Outcome from application:
Feed into future work

- Digital stories used as evidence at ethics panels and Public Benefit and Privacy panels (PBPP)

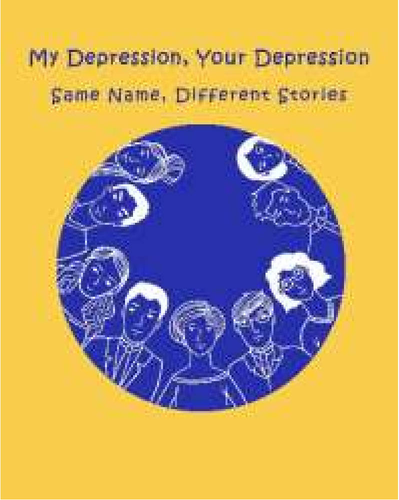
This has not yet been achieved, but as more stories are made and uploaded to the Patient Voices website, we hope to do this in the future.

7. Additional Information

Please include any relevant information and/or links here relating to your project, which could be used to raise awareness of your project work to others.

For example: links to an online resource, a film, internal/ external communications, news coverage or social media posts about the project; quotes from project partners or public participants/ audiences.
Please send/share relevant high-quality images/ photographs of the project 'in action' and/or project team.

Project Image:



Digital Stories can be found online at:
https://www.patientvoices.org.uk/mydepyourdep.htm

There are lots of quotes etc listed in the sections above that could be used to raise awareness of our project to others.