RESEARCH AS A HEALING PRACTICE

Mental Health & Data: Imagining Beyond
Community Wellbeing Collective

Contents

Community Created Methodolgy

The Community Wellbeing Collective (CWC) is a durational social art collective of 30+ people living in and connected to Wester Hailes. It is a diverse, intergenerational, intercultural, working-class organisation. We came together to practice what community wellbeing can be, expand public imagination, and take agency on common struggles and desires.

We share our diverse talents in the collective running of a Community Wellbeing Space, where we run monthly Anchor Events which explore the wider politics of wellbeing and free community wellbeing activities. Our work is an immediate and significant local action in itself, but it also acts to address the effect of intersecting oppressions on our mental health, creating space to breathe and the possibility to dream together and take action towards structural change.

It's safe to say that we do a lot! And in this zine we are sharing our work as community researchers in an exploration: Mental Health, Knowledge and Imagining Beyond, Community Created Questions and Methodology

The CWC was approached by Iona Beange, the Knowledge Exchange and Impact Officer for the Mental Health Data Science Group in the Division of Psychiatry at The University of Edinburgh, to be part of research funded by Research Data Scotland, relating to public opinion about mental health data sharing.

From the beginning, we established some important approaches:

- we would use Social Practice methodology where the outcomes are not assumed but emerge from a process of understanding and acting upon common urgencies
- CWC members could be the researchers, rather than subjects to be researched
- the sharing of any data collected would be determined by the CWC researchers and other participants guided by their wishes for the impact that it could have.

There are some practical elements of our methodology which are not separate from the values underpinning our other approaches, but arise from and feed into one another, these include:

- an open invitation to all members to join the research process as well as reaching out to individuals
- meeting at times that is most suitable for the group considering all of our work and caring responsibilities
- holding check-ins and check-outs (opportunity for each person to say a little about how they are at the start and end of each session)
- making payments available to cover all of our time because we understand this work is valuable and not always possible on a voluntary basis
- providing child care making this work accessible to working-class parents and single parents, who are often women, and people of colour
- offering refreshments so that we can all have the energy and comfort to work
- provide meals when working over meal times because we wouldn't assume people would have one otherwise
- creating a welcoming environment because we understand accessibility is also about how we feel in a room
- scheduling comfort breaks because we need time to rest, reflect and be flexible to adjust the plan if needed

In this way we formed a group of 11 CWC members with lived experience of the theme, with a range of ages, beliefs, life experiences and home countries. The group met for a series of workshops to understand perspectives on Mental Health and Data, generate research questions based on what we felt was urgent for our community and the current social political situation. The CWC research group and the Mental Health Data Science Group had exchanges as we visited each other's spaces and shared learnings. These were engaged, active experiences, as the CWC is guided by an approach of no observers, only participants

The Community Wellbeing Collective and this research group are spaces where together we build multiple possibilities for taking action in the world. So what emerged from this process was individuals and small groups pursuing different questions with different approaches, producing an explosive range of learnings and results. Some members worked with professional researchers to carry out research, exchange knowledge and reflections as the research unfolded, or/and understand and analyze data after the research had been carried out. The Community Wellbeing Collective and this research group are also spaces where we understand and build common practices, so we continued to develop a general methodology alongside the specific approaches.

Our methodology is described by CWC member and artist researcher Federica Cologna as 'informed by the way we work and are a collective taking action towards community wellbeing possibilities. The space we hold as a collective is a brave and vulnerable one, which makes it raw and responsive to the lived and the felt. The research we do is, therefore, an embodied practice, shaped on individual and collective lived experiences of mental health and placed in conversation. We practice deep listening, we share and relate through questions, anecdotes and emotions to connect across differences and through needs and desires. As a collective we create a space where we can meet and dialogue taking care of each other's needs to make everyone feel seen and heard, believed, respected and safe.'

Members were tackling questions that were relevant to their lived experience. We have an embodied understanding of the emotional and material crisis we all face today and the very urgent need for healing, as well as being people with very expansive, often creative, collective wellbeing practices. We cannot wait for a data set to influence policy, we must take matters into our own hands. We are in an emergency that has gone on for more time than the meaning of that word can contain, so the action we take comes with immediacy and a steadfast patience in all routes to change. Many in the group spoke about sharing being healing, both for the person who is experiencing emotional struggle and for others to learn from their story. The activities this research group designed to gather data allowed for people to express, listen, find empathy and be together. It is healing on personal, community and structural scales.

In order to create this space of trust we must understand and build our common motivations as well as developing a mode of listening that can include multiple realities and knowledges. This is opposed to the data collection we are used to, which can involve limited expression of complex experiences in situations where we may not know that data is being collected, do not understand the motivations of the data collecting, or we understand that their motivations are sometimes even in opposition to our own healing and wellbeing, in the case of data collection for surveillance, incarceration, advertisement and private profit.

Approaching research in a different way challenged accepted frameworks of mental health data and created the possibility for people to share honestly about their mental health, resulting in accurate and expansive data as a tool of change, as well as the immediate process of data collection being healing. We create space for radical questions, where we can work together to understand the struggles in the current systems, and imagine beyond them. We extend the invitation to those reading to be in touch and join in conversation and action.

Written by Josie Tothill, drawing together threads by Federica Cologna and the Mental Health - Imagaining Beyond CWC Research Group.

Evaluation Transcripts

In the initial workshop we planned to ask some evaluation questions that would be repeated at the end of the project. The CWC, always surprising and responsive to what emerges, went beyond evaluation. Due to the space of care we created together people responded with deep wisdom, rigorous knowledge and personal experiences. The recorded answers furthered our research and became a different kind of data with new sensitivity and creative and intellectual authorship. Because of this change, we felt it important to give the opportunity for everyone to look back on, confirm, clarify, or redact their words, and decide what and how we wished to share.

The group decided that to retain ownership over our words, avoid being taken out of context, prevent issues around secondary data sharing, and keep confidentiality, everything we would share would be what we were happy to share with the world, individuals would be anonymous and the words would be credited to The Community Wellbeing Collective Mental Health Research Group.

What do you think when we say the word ‘knowledge’?

‘I think about how the stories we share can bring about space and conversations of deep ancestral knowledge.’

We can gain knowledge through education, books, and through community, through relationships. I also believe in knowledge coming from the senses, from emotions, from the body and from people coming together, from many different aspects of life. Important questions that I ask myself when thinking about knowledge are: who is producing the knowledge? Who has access to knowledge? How can we produce knowledge? Who is the owner of knowledge?’

What do you think when we say the word ‘data’?

Data makes me think of recording storage and online data is maybe advancing a bit too fast and real quick not fully understanding how our information is being processed … it makes me feel a little bit overwhelmed and don’t quit know how it’s gonna affect me or if it will affect me later I’m just hoping that it won’t and leaving it at that.

I think that in a lot of cases the sharing about what gets called mental health is like a healing act in itself and then I don’t feel that when we think about the sharing of data.

Who do you trust with data about your mental health? Who don’t you trust?

People who have a shared struggle with me or shared aims and desire to change what’s happening in the world that’s who I would trust with data. And so I think being involved in the process is the only way that you can know that, even if that’s on a very large scale and you don’t literally know a person who is looking at it.

I wouldn’t want to experience limitation or exceptions from certain benefits due to the fact that my mental health data was shared To the wrong People or department. So I say I would like my consent and what impact it will have on me.

It's probably the least likely place that I would share my mental health would be an doctors surgery for example and I’d probably be more likely to go to a friend or someone I feel safe to talk to.

I would feel comfortable in sharing some data in this group or with CWC members because I know we have some shared values and commitments. I know that CWC is a brave space in which mental health stories could be shared for good purposes.

How do you feel about considering your knowledge, expertise and experience as valid research?

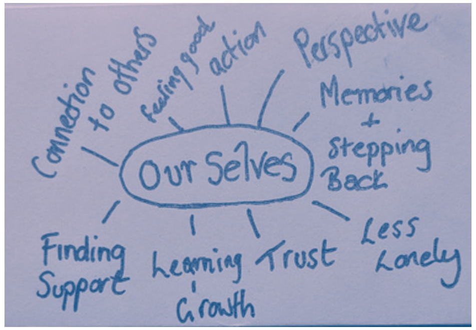
so I say only those who feels it knows it. so being an expert of your own mental health is the experience and the journey you’ve gone through and how you were able to handle it to find yourself again. If we are to be experts on mental health we should be able to tell a story/experience to make people comfortable to relate and open up.

I feel there is a lot of unheard and unrevealed wisdom and knowledge that we, as part of a community who came together around wellbeing, can generate.

> “ I think sadly, that all the institutions that you think that you can trust and are brought up to believe you could trust, such as the NHS, police, lawyers, mental health institutions. The ones that you would think fundamentally and absolutely, are the place to go for safety, are not in my experience. Coming into a collective of people, like we are today, and sharing our experience of mental health and what that looks like, feels far more safe to me ”

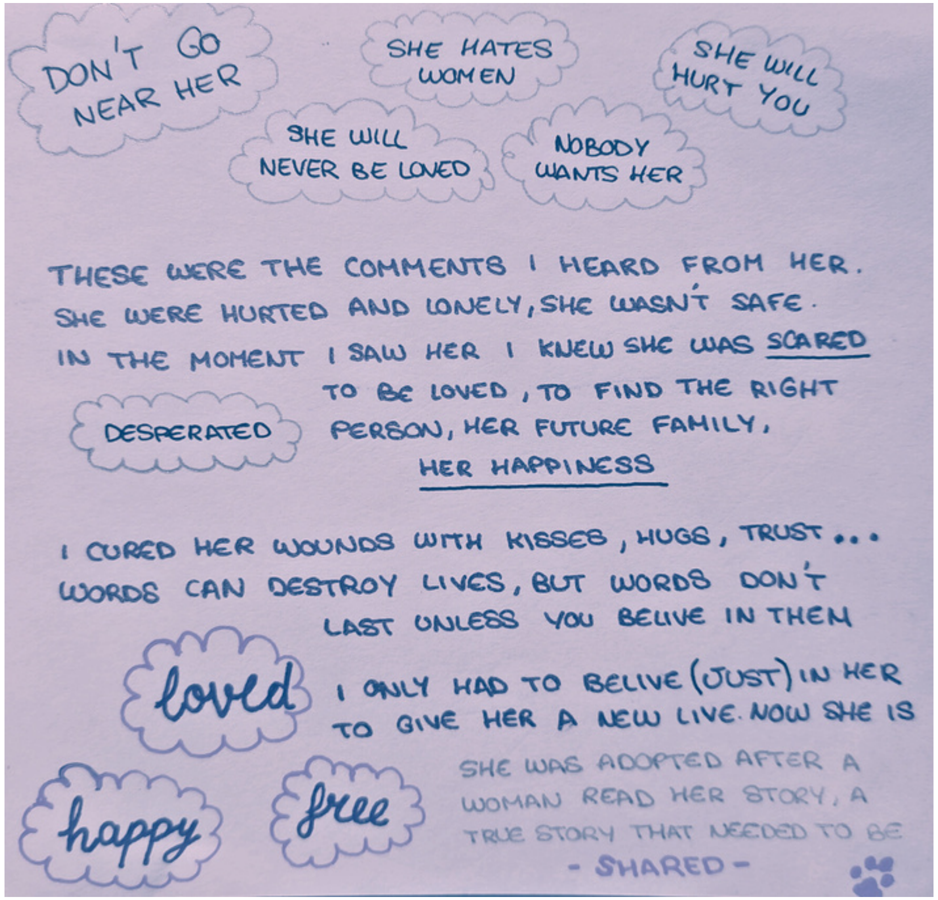
How Can Sharing Be Healing for Ourselves and the World?

The community created question that CWC member Maryanne chose to research was, how can sharing be healing for ourselves and the world? Maryanne, facilitated 3 workshops in which participants considered this question before sharing their own stories verbally and through creating story books. The group's response to the question was also recorded in the form of a mind map. This report looks at what can be learned from this experience taking the data from all research.



It is clear that participants could see multiple benefits from sharing stories, particularly following traumatic experiences. However, warmth and positivity dominated the stories. This would appear to endorse the value and importance of opportunities to share and be heard.

Research by Maryanne Jacobs, extracts from thematic analysis of research by Dr Deborah Holt, Lecturer in Mental Health Promotion and Health and Wellbeing, University of Edinburgh



DON'T GO NEAR HER

SHE HATES WOMEN

SHE WILL HURT YOU

SHE WILL NEVER BE LOVED

NOBODY WANTS HER

THESE WERE THE COMMENTS I HEARD FROM HER.
SHE WERE HURTED AND LONELY, SHE WASN'T SAFE.
IN THE MOMENT I SAW HER I KNEW SHE WAS SCARED
TO BE LOVED, TO FIND THE RIGHT
PERSON, HER FUTURE FAMILY,
HER HAPPINESS

DESPERATED

I CURED HER WOUNDS WITH KISSES, HUGS, TRUST...
WORDS CAN DESTROY LIVES, BUT WORDS DON'T
LAST UNLESS YOU BELIVE IN THEM

loved

I ONLY HAD TO BELIVE (JUST) IN HER
TO GIVE HER A NEW LIVE. NOW SHE IS

happy

free

SHE WAS ADOPTED AFTER A
WOMAN READ HER STORY, A
TRUE STORY THAT NEEDED TO BE
- SHARED -

Toolkit Towards Emotional Safety

Working Together

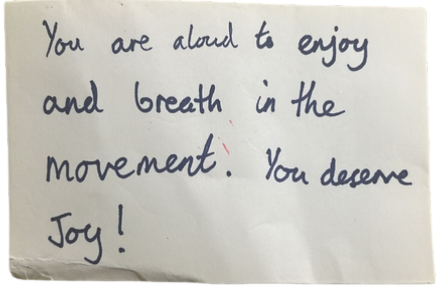
- Listen to each other, and try not to speak over others
- Be aware that we have different ways of acting, feeling and speaking
- Be open minded and remember everybody has hardship
- We understand the power of sharing as a radical act but know it's ok not to share
- Recognise that people have different capabilities and modes of sharing (writing, speaking, in groups or not,) and we strive to create the possibility to share at a later date
- Respect each other boundaries
- Allow for doubt
- There is always the possibility for pause, respite, and exit which we will take if needed
- Plan for time for discussion, be prepared to be flexible
- Remember there are no wrong questions, just routes to further exploration
- Try to create a space that is actively non-judgemental, so that we can all feel safer to express ourselves more authentically
- Be aware of any judgement we may feel and move towards curiosity instead
- Do our best to let go of guessing what others are thinking
- Remember that spending time together is important

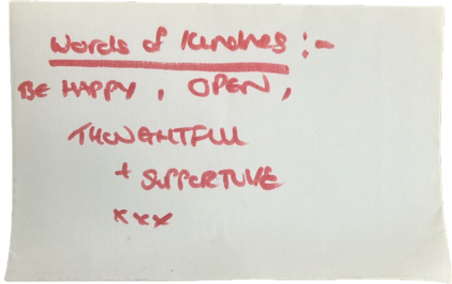
Boundaries and public work

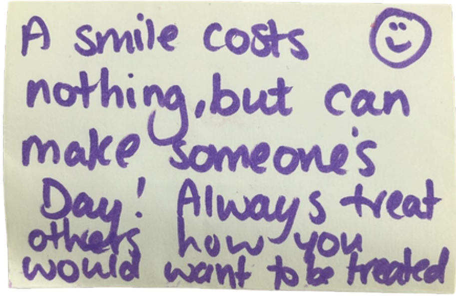
- We know it can be very vulnerable to share so will consider if we should invite sharing and of what kind
- We know it can be important to build trust so where appropriate we will work with people we already know, or take the time to build trust and create opportunity for remeeting
- We will not do lone working with the public
- As we create space of care will remember we are not here to diagnose, cure or care for anybody
- We will interrupt conversations that are beyond our capacity
- We will consider when it can be important to show sympathy and softness
- Let people feel listened to

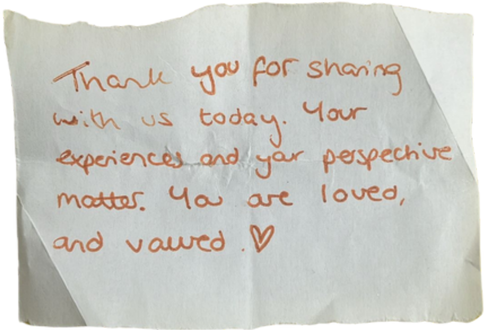
Care for self

- Do what we can to be aware of our own triggers, struggles and limits and step back when we need to
- Do what we can to be aware of compartmentalising and where it is healthy or not for us
- Recognise we might not know how we feel at the moment and take time to process
- After work or research sessions check in with yourself to see if you need aftercare

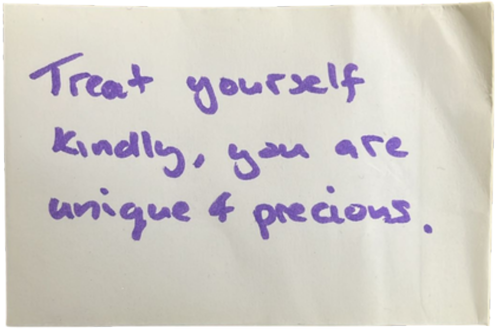

You are aloud to enjoy
and breath in the
movement. You deserve
Joy!


Words of kindnes :-
BE HAPPY, OPEN,
THOUGHTFULL
+ SUPPORTIVE
xxx


A smile costs nothing, but can
make someone's
Day! Always treat
others how you
would want to be treated


Thank you for sharing
with us today. Your
experiences and your perspective
matter. You are loved,
and valued. ♡

Words of Kindess

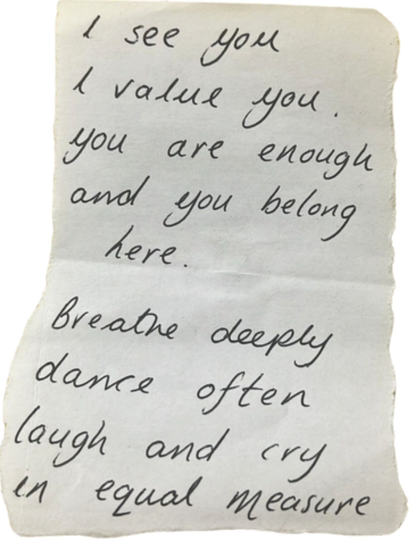

Treat yourself
kindly, you are
unique & precious.

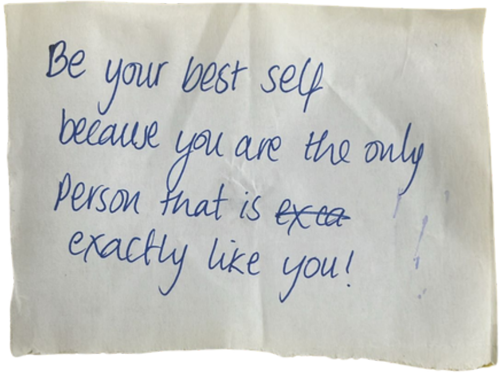
Acts of kindness can make the world a happier place for everyone. They can boost feelings of confidence, being in control, happiness and optimism. They may also encourage others to repeat the good deeds they've experienced themselves - contributing to a more positive community.

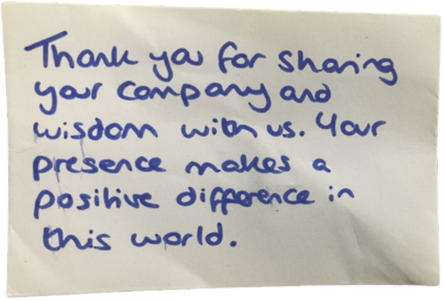
'Words of Kindness' is an exercise that you can do at work at the beginning of activities or meetings. It involves everyone writing words of kindness anonymously on paper and putting them in a bowl, and then picking them out randomly at the end of your work meeting. Each individual then reads what they have picked and decides if they would like to keep it.

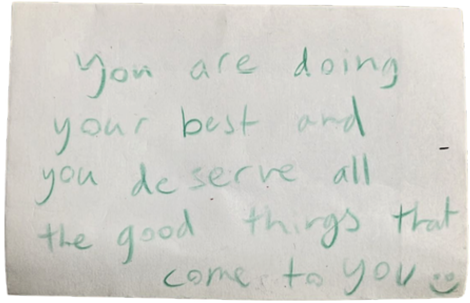
by Jogob Sarr

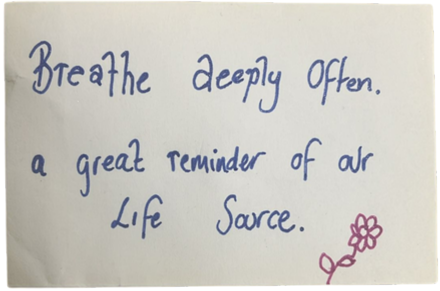

I'm
Listening


I see you
I value you.
you are enough
and you belong
here.
Breathe deeply
dance often
laugh and cry
in equal measure


Be your best self
because you are the only
person that is ~~exca~~
exactly like you!

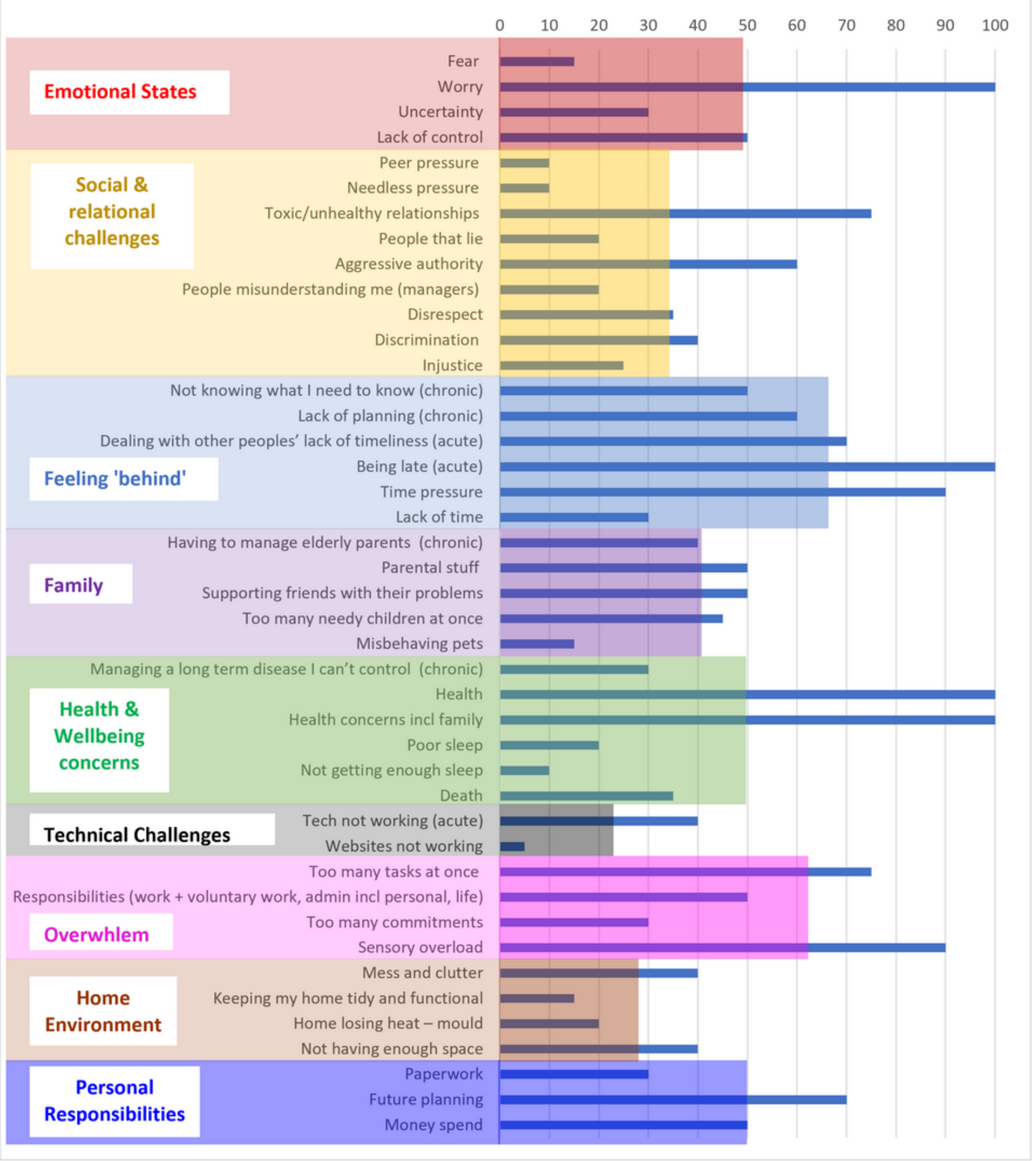

Thank you for sharing
your company and
wisdom with us. Your
presence makes a
positive difference in
this world.


You are doing
your best and
you deserve all
the good things that
come to you ☺


Breathe deeply Often.
a great reminder of our
Life Source.

What Causes Us Stress?

Research by CWC members Sarah Norman and Rumilla



"Where was I when this question was asked?" – Rumilla

The question above is so important and when Rumilla asked it, it really hit me hard. I was appalled when Iona told us that research on stress was most likely to be based on white university-educated women.

It's great that we know (at least as much as current academic structures allow us) how stress affects white university-educated women, but that leaves out literally everyone else.

Whose experiences are we missing out? What could we learn from listening to different stories through different structures? How could simply being invited to speak and be heard about experiences of stress positively impact stress levels and their roots?

One side note as part of this: We could literally ask where people were when a question was asked – some people may be taking care of their children or at work instead of being on channels where recruitment for stress research takes place. This could give us insight as to why so many voices are not being heard in academia.

Iona Beange provided the CWC with a list of 'Stressful life events' that researchers consider are the most likely to trigger depressoin / mental illness. These are based on a paper by Brugha T, et al (1985) doi: 10.1017/s003329170002105x.

They are separated into 2 types:

- Dependent Life events are those in which the person plays an active role (NB: this does not mean it is their fault, it just means they are involved)
- Independent life events are things that happen to you, over which you have no involvement.

Dependent Life Events

Did you have a serious problem with a close friend, neighbour or relative?

Did you have a separation due to marital difficulties or break off a steady relationship?

Were you made redundant or sacked from your job?

Were you seeking work without success for more than one month?

Did you have a major financial crisis such as losing the equivalent of three months' income?

Did you have problems with the police involving a court appearance?

Independent Life Events

Did a serious illness, injury or assault happen to a close relative?

Did a parent, spouse (or partner), child, brother, or sister of yours die

Did a close family friend or relative die, such as an aunt, cousin or grandparent?

Was something you valued lost or stolen?

Did you suffer from a serious illness, injury or assault?

> *“For this research, we want to equalise it. Not focusing specifically on marginalised people, but just including them in the data pool.” – Rumilla*

Our Questions:

After much deliberation and discussion, we settled on a 3 part question for this pilot:

What makes you stressed?
Where do you understand your stress to be?
How do you deal with stress?

> *“Talking about stress wasn’t what I needed to do to overcome it. If you do care I don’t want you to worry, and if you don’t care I don’t want you to know.”*
> *– Rumilla*

Our main aim was to ask the people, where do YOU experience it, and where do YOU group it – short or long term/ everyday or life stress. We asked how they think things group into these categories, and perhaps even allow them to identify what they feel these categories look like and define them themselves.

How do we define long term/life events – is it your increased likelihood of mental illness, as in current research or just something that affects who you are today? This would be a more social model of mental illness: it’s not that you’re ill, it’s that you’ve experienced something that affects you today.

By allowing our participants to help define terms and shape the research alongside us, we actively involved them in creating a bottom-up approach to mental health research far from the prescriptive approaches that we are used to.

We aimed to find and amplify voices of people who have previously been disregarded and neglected in mental health research to empower them to have a direct hand in how it is carried out.

Thinking Through Research Processes and Methods in Community

Federica Cologna, Bobby Sayers and Josie Tothill from the Community Wellbeing Collective (CWC) in conversation with Knowledge Exchange & Impact Officer Iona Beange and Senior Data Scientist Matthew Iveson for the University of Edinburgh

Federica Cologna: In preparation for this conversation Matthew shared his interest in discussing **how the research process can empower participants**. This could be a prompt for us to start reflecting together about **what empowerment means in research for participants and researchers? And how can this empowerment be mutual? Or what are the tangible benefits for the participants’ community in this kind of research?**

Matthew Iveson: I guess my question was born from the idea that most of the time when you engage with the Public as a researcher, a lot of this engagement is about explaining. You're explaining to the Public stuff we've done or stuff we want to do. I think what I would love more is for the Public, that being with capital P, to be able to ask questions about research generally, as well as about the project, and also to generate questions that then drive the research. So, rather than me saying: ‘I've done this thing! What do you think of it?’, I would like the Public saying: ‘You should be doing this thing’, and me saying: ‘Oh, why should I be doing that thing?’. So, then it becomes more of a kind of dialogue. **I like the idea that research can somehow upskill people.** One of the things we've done with some of the patient and lived-experience panels that we run is that we train them in general data science methods, and we give them glossaries and information about all the acronyms, so they could technically go and read research papers. That's the sort of skill that I’d really like the Public to have more generally. **Not just awareness of research, but actually being able to criticise research and being able to generate their own research ideas and content.**

FC: Does anyone want to respond to this?

Bobby Sayers: Yes! So, I think that with the Community Wellbeing Collective (CWC) this pilot of mental health and data research, which wasn't just about mental health and data research, was about **how could we, as CWC as a community group, as people who we know have expertise but aren't trained in forms of more academic research or scientific**

research, create a process? So, yes, I feel like that and this was exactly what happened, exactly what you said, which was asking questions about the research process and then everyone generating their own questions that would be of interest around mental health and data. Because of the fixed term of the project, the process stopped now, and we're learning about that ourselves, about how those research processes take place, but that essentially would have been the whole process that we would have carried on and worked with those questions that people had developed. Even to understand that process from the start was really powerful. There were lots of elements in it, and **there was one person who was also quite sceptical about the whole process, and they had questions such as 'Where's this research actually going to go?', which became really important.**

Josie Tothill: I think all of these things are absolutely right and, this person came to my mind as well, because it sounded like that there's a sort of gap or just a difference between the different knowledge of a researcher and someone who might be generating the data, and a participant in the research. So, **there are different kinds of knowledge and bridging that gap**, I think, is really important and I also think about it. This is not at all to patronise, this is to bring respect. I also experience this myself, like… how a child might ask the right questions like the key questions, the questions you don't actually have the answers for as in our research process. I think it was a lot of us, including myself, who have some inexperience that then generated really important questions, and actually really moved the research forward and kept it in check as well, especially on an ethical side. So, I think that is one source of power or ability, and maybe power or ability to change and to create change, to change course, to change direction. And I think a lot about what our collective power is. Also, it's super cheesy, but the idea of **knowledge is power**…. so, everyone's lived experience is real wisdom to draw on, to create change, and so to then be respected as that. We talked a bit also about authorship, and not being it only data points, but actually like the data that we were generating was also really in depth, you know, like not essays because they weren't structured like that, but the content you might find in essays about some of the issues that we were tackling and dealing with; **so like having a sort of authorship, even if it's a collective authorship to be able to anonymize yourself in the data**, I think, was also something that came out of our process. I thought it was really interesting that you said that a lot of the engagement is like explaining stuff because **I think that that kind of knowledge sharing is, in a way, like resource sharing.** But at the same time, I can imagine it can be difficult to not want to just be serving someone something like 'here's my expertise, and here's my expertise' like over and over again. I just think that it was absolutely amazing how all of the researchers who came to our September anchor event shared knowledge in a way that was super accessible. It was so generous. **I think that worked because we also had understood what our shared interests and urgencies are; so I think that finding commonality and finding what's important to share and sharing both ways can be very important.** This idea of explaining, I would still be more curious about it now, and what I think would be really important is to explain and to share this resource of knowledge of how this whole thing is structured; because to me it's not necessarily like we need ordinary people to be writing research papers or to be able to be critical of research papers, because that's already a structure that people can step into. Whereas, like understanding the foundation that this structure is built on, and then being able to say: 'is this what we want? or what we want to create?' I think it is important, and any knowledge that can be shared in a free exchange about that is so valuable. We had an event aside from this research project last Saturday, and someone spoke in a very moving way about what's happening in Palestine right now, and one of the things he said was follow the resources, like follow the money, I think they put it. So, I also think that I would be more curious about sharing that knowledge more widely about **how research is funded, to what ends and whose interests have been served, in what way and how can we make it towards our collective interest of change being served?** And for researchers who are in that system, and who understand it to be able to share their knowledge about it and share that power to change, I think, is and would be amazing. I think we've done some of that already, but that's something that I would be quite interested in, which also, maybe expands also what we can consider research. Also, thinking about **the work that Federica does as an art worker and researcher, the way that those things are intertwined,** I think, has a lot to open up that conversation as well.

MI: I was just going to say that the funding aspect is a really interesting part of the world that researchers live in, but it's like the bit of the iceberg that's under the surface. I think it's one of those places that patients and the Public don't really understand how much power they actually do have in that sort of situation. Because, **as a researcher, if you want to get funding you need to prove that the thing that you're doing is in the Public interest** and is something that the Public are actually interested in, and that it's going to benefit them. And all it takes is for somebody to say: 'No, we're not interested in that' or 'No. This isn't a good idea' and that project probably won't get funded. So, I think making that power dynamic more obvious to the Public and to patients is probably a really good thing because that would get more engagement from the ground level in generating research . questions and such ideas, but also **getting more involved with the actual funders** who have the responsibility of handing out the money as well. **They also have their own Public engagement** PPIE (Patient and Public Involvement and Engagement) sort of angles, but it's rare to come across a patient that's heard of them? I don't know

JT: How? I just have a question which is…. I think the idea of **power also being** like **learning where your power is,** and understanding that, is really beautiful. But then if the Public do have to say this, you know, **if you need to prove that it's in Public interest, how is it? How do typically researchers show that or ask that to the Public?**

MI: There's a charitable organisation that has a patient and Public derived list of research questions under each kind of topic [James Lind Alliance (nihr.ac.uk)]. So, you can kind of go to a readymade list of research questions, or at least the kind of research areas that Public are interested in. **But generally, you're encouraged to, or in some cases required to, demonstrate that you've spoken to a group of affected people** about the thing that you're about to talk about and are about to get money for. So, if I was doing a project on depression, I'd have to go and talk to people with lived experience of depression, or it wouldn't make sense. And if you haven't done that, or if you've done that, and people say 'No, that is a terrible idea' that sinks the entire endeavour. Nobody's going to give you money for something that the Public don't agree with. Yeah, that's it.

Iona Beange: I guess a big part of this particular project was exploration for me, and **what could happen if we allowed a group to generate some questions, and where could it go?** I guess the nice thing about this particular funding is that it was very open, it wasn't too closed in, and so we had a bit of freedom. Some funding is very closed, and you can't do this. You can't do this kind of slightly freer and a lot of the goals of a project are set in stone as part of the funding, you know, and generally funders will hold you to account for the things that you said and agreed. There's basically no flexibility about, you know, changing to have an output that is totally different to the kind of things you said you were going to do. There's basically none of that. **If you don't do the things that you said you're going to do then you probably don't get funded next time. That's unfortunately the way the system works. So, when we shape research, we tend to do it beforehand rather than during the process**, but I agree that it would be much nicer to do it as things go along. And yeah, I just don't know how that works in practice.

BS: So more than the word nicer, I personally, have a really deep interest in this idea of what we call in social practice co-production methodology. So, not everyone takes the durational or like community embedded approach as, for example, **Jeanne van Heeswijk, who's a researcher and artist that we worked with, who is particularly interested in how a community shapes the outcomes that they want.** But that is the methodology that interests me as well. There are a lot of people who write about that. And I just think how that could be expanded beyond the field of social practice, integrated into other research fields. I would be super interested because I actually don't know so many academic books that talk about this, this challenge, like challenging the forms of methodology. So, I would be really interested if people have references.

IB: I don't know about references. But I can say that there is a patient and Public involvement group at the University of Edinburgh, and we have had similar conversations to this about where can we find funding, or where can we find time and space (which kind of comes back to funding) for these kinds of explorations? Because increasingly funders are asking: Have you talked to any patients about this to see if they think this research is important?' That's like boxes that you're starting to see in grant applications, but there is very little by way of pre-funding you. You kind of have to do that on the tail end of your previous funding. You almost kind of have to hide it. I mean, **the research process is such that employment tends to go on kind of 2, 3, 4-year, if you're lucky, 5-year cycles and so part of your time towards the end of one grant is spent on writing the next one in that process.** I mean, you come across that with CWC as well. I'm sure that you end up spending your time, at least towards the end, focused on getting the next one, but **there's no real money set aside. There's no time set aside for these kinds of discussions, yet increasingly they [funders] are asking for them to be there.** I did put this in a funding bid a few months ago, and it was rejected unfortunately for not being innovative enough, but there we are. It was with the University, one of the internal funding to try and get money to do this, to run some sessions to bring groups together, to explore what issues are important around mental health and to try to plug people into… a bit like we've started to do here. We started to plug researchers in with particular individuals who are interested in that topic. It was about doing that on a slightly wider basis. Unfortunately, that funding was not achieved, but I think sometimes it is those wider networks that possibly have a little bit of leeway to do that… so they're embedded in a topic, and our mental health is embedded in a mental health topic… So, I'm trying now, just kind of plucking groups off the top of my head, but it's finding the funding to apply for. That's the really tricky thing.

JT: Yeah, it sounds really tricky, and I guess I have some thoughts… I first wanted to ask if you guys know why? Like, if it's expected that you do have conversations with the Public who have lived experience of the research topic and that's necessary, then why is the funding weighted, not on that side of it, but only

explorations. So that was nice within this funding. And **it's really lovely to see that there are potential collaborations setting up and that, fingers crossed, will continue.** So last week I met with Dr Pippa Thomson, who's a researcher and with Sarah (CWC) and Rumilla (CWC). There was a really nice conversation there, and some potential for that relationship to carry on into a funding grant. I think there'll be emails and conversations about that carrying on. So, it's really nice from my perspective to see that this might be shoots and sprouts rather than necessarily a closed of a process by itself. Ok, it was only a short bit of time, but they were seeing it as bringing people together to see what could happen. That was one example, and then Maryanne (CWC) met with a social science researcher called Deborah Holt last week. On Friday they met together, and Maryanne showed some beautiful booklets that had been made during the sessions at the CWC. They were looking at them to see what they could do, and they started the process of thematic analysis, which is a social science method. So, they started that process looking at the booklets and some of the materials that were generated there. **There was some real skills-sharing happening** in that session on Friday but with a very open, empowering atmosphere between the two. **There was real respect**, I think, **is what I observed both ways and it felt empowering.** I couldn't stay for the whole session, but what I saw felt really lovely and empowering and that's the sort of thing I'd like to see happening and just bringing people together… that mutual respect and seeing where it goes, seeing where it can go.

FC: This brings back to what Matthew was saying at the very start of the session which is this kind of **upskilling and skills sharing as a way of mutual empowering between researchers and participants or co-researchers.** Or what does it mean to be a participant? Which kind of names do we want to use in these research contexts? In a way, we share resources and skills from both sides, and then we explore what can happen… **and I really like also the idea that Matthew shared before about asking general questions on research, like how is research done? Or how do we generate questions?** This is also empowerment to me, or sharing power, it is also **giving the time and freedom and space to ask these general questions to let some doubts grow about how we work and how we carry out research** within the structure that is put in place for us. How can we approach the structure differently? And **how can we ask for funding that allows more of this freedom and that is not project-based with a linear timeline**, which many times does not allow to ask these general questions, but only allow for people to jump in within specific questions and explanations and structures that are already there. And so, then it becomes more of a kind of hierarchical or a kind of research-extraction.

BS: Yes, that makes me think about **how can research not have set outputs at the beginning** or set things that need to be achieved yet there be like a certain parameter of the field where the interest lies that allows for the process of research to shape the outcome, because then the outcome can be mutual, you know… like if the outcome for CWC could be that we are able to produce a booklet that has certain ideas or thoughts around well-being, and has some sort of advice and tips and other things, and that gets distributed to x amount of households in an area, and then for the researchers that booklet holds for the research funders that research that was done to achieve that, you know. Like, it is just a random example, but **it makes me think a lot about outputs, you know, and impact** as two really important things.

MI: Yeah, it's really interesting. I like the idea of shaping outputs as part of the dialogue. A lot of the outputs of a project, on the other side of it, like, what produced that?

MI: Yeah, I think Iona is right. **So historically, there would be no patient and Public engagement involvement at all. It would be enough to say that this is a really interesting scientific question. Things have evolved but in the way that things typically evolve… stuff gets added on rather than fundamentally changed, and so I think that's probably why you see the system we have.** I think what's becoming more common to Bobby's point about co-production is this idea of **a lived experience co-investigator**, that sort of thing. I think that's really good in the sense that they are **usually involved in the design of the project that you apply for money for**, so that they kind of design the deliverables much like a researcher would; and they're involved in the day-to-day kind of decisions of the project, you know… 'we can decide that we shouldn't look at it this way, but we should look at it that way', **but it still doesn't change the fact that there is no flexibility really about the deliverables**. You can't just suddenly change things, and I don't know how that would ever be fixed. **The way that I would love things to work is that as a researcher my employer is the Public, and they have some greater control over where the money goes** because then, if I talk to the Public and figure out what's important, I can do the legwork for them, you know, they can come up with some ideas. I can do some leg work and say: 'this is what I find', and then they get to decide whether it's useful. But yeah, that's not how things work. The funders and the Public are like separate entities, and there's no accountability to the Public in the same way that there's accountability to the funder.

JT: I guess, I know we don't want to put the words into your mouth, but what I would take from that, and how I would put it is that **research needs to be nationalised and democratised. Maybe that is something I would say, but then the question is how?** Another big one.

FC: I suppose that the exploratory work that we have been doing like this kind of space we are opening to question the way we work should bounce off on the other level like… **how funders could open this similar space and co-plan funding based on needs and requests?** Also because **if they are asking for engagement with communities, then they need to understand what is needed for this engagement** and what they offer as a funding body to do that work needs to respond to the request coming from the people taking up this work. So, perhaps the exploratory work we have been doing needs to happen in a parallel way also on that kind of structural level.

JT: I wonder if we can learn anything from what Bobby says, from social practice methodologies. There's Owen Griffiths, who talks at least informally, but I think also as part of his understanding of his practice, **about hacking** which I find quite interesting. **You can hack sort of like arts funding and then he goes on and for example he works with gardens,** which I do see differently because I **see that also as art** like he does as well. So, I maybe wouldn't always use that exact word, but like the idea of hacking, I wonder how that could be applied to research and things like this, because this exploratory work that we've done as part of this project has been amazing and such an incredible opportunity, and I think I am also interested as well in how what we do can advocate for the change that is needed… so like how our struggle for funding is also like not only a struggle, but a way to **advocate for changes within the funding landscape, and trying to do that work of activism and campaign and change alongside the work of the day-to-day and then meeting what we need in the immediate moment as well. So, I just wonder how that could work within research.**

IB: I've put one example in the chat. So, this was about rare conditions and people with rare diseases. It's in Cambridge [Patient Led Research hub - https://plrh.org/]. It's like a hub that got a set amount of funding which they could then distribute, and they could then use, and they took in suggestions from patient organisations and charities and groups like that, and then they matched them up with researchers and distributed funds that way. And I think there are a couple of organisations who have done similar work. So, Scotpen was another one, who applied for funding in a slightly different way, as a public engagement one, but they sort of applied for funding from the Wellcome Trust, and then they distributed it out. **If you could get trusted by a funding body to then become the distributor. I think that's the only model I've seen** that's even close to this. And it's not quite this, but it's closer than possibly what we've got at the moment.

JT: Wow! That's really interesting. Because then, **I wonder what kind of commissions you can make, and how it can become credible as well.** So like we have worked with a really amazing filmmaker, called Rachel McBrinn, who works each year with the Edinburgh Art Festival, which is why we know her, and we've been in conversation about work that she's doing at the moment around creating community archives within film and people being able to control their own narrative, but also this being towards changing their environment… and like the films themselves being like campaign pieces, but also being like something that can be part of evaluation internally, but also reporting back to funders and it just sounds like really really interesting but **a lot about the people being able to tell their own stories, share their own knowledge, and to then build their power… but then that idea of how that could be paired with something like thematic analysis, or something like this to generate, then, like actual credible research, and how the arts can be part of that…** I wonder what CWC would do with that kind of money and with that kind of power to distribute… I think it's really interesting.

BS: Yeah, maybe that would be a question actually, that I would have like… **What validates research and what doesn't?** I mean, I'm sure it's a huge question. It's not my field of knowledge, and I know that there are research papers, and once something gets accepted for these then it is research.

MI: So generally, with a project, **a fund that will expect you to show that you've met all your deliverables.** So, if you say that you're going to produce a study on incidence of depression by deprivation in Scotland, they will expect you to have done that. **The way you evidence that is by saying: 'we published these papers on it in an academic journal' or 'we've shown our findings at these conferences'. Usually, the PPIE (Patient and Public Involvement and Engagement) elements of it tend to be separate**; because you want to be able to demonstrate that it's not just part of one little bullet point, but it's part of the whole thing. So, if you say 'we had a workshop with some people with lived experience' that's a tiny part of the project… Yes, great, but it's not enough to quantify the impact of a project. So, papers are definitely part of it. In the current academic climate, they're necessary. It's like the evidence that you did something out in the real world, and you know they're measurable and all that sort of stuff. And so, they're quite easy kinds of markers for success.

IB: There's different qualities of journals that you can get published in as well. So, for example, I did publish some Public engagement things in *Wellcome Open Research*, but it's got quite a low sort of ranking, if you like. If I was to quote that and say 'give me more funding, I've got papers in Wellcome Open Research' that wouldn't be so well respected, whereas if I said 'I've got papers in Nature or Science…' **There is a kind of ranking system even within journals of which ones are regarded as the best.** It differs with your field, which field you're in, but there is a kind of hierarchy as well. A lot of it helps down to how it happened before, which is a bit unfair…. But you start out relying on your supervisors' publishing history and you gradually gain your own over time. Is that right, Matthew?

MI: Yes, essentially, yes. So, we tend to use this word 'impact' when we're talking about journals, which doesn't really mean what impact should mean. It just means how popular is the journal and **so when we talk about 'I've had a really impactful set of outputs from this project' it actually usually means, you know, how often did you get mentioned by other scientists?** How often did your stuff get read by other scientists?

JT: Which is to me quite interesting, because then it's like, all of the value systems for what impact means is already within the world that's already been created. But I don't know if you guys know, **there's a journal called *Lumpen*, which is like a working-class journal and people write really really amazing articles, and it probably has more people reading it.** And it's, you know, it's in print and everything. Probably more people read it than a lot of academic research that's published and that is referenced a lot. So, it's also like, but I think it's something to create a framework around… I also do believe in things being trusted. Maybe it's the right word. I can say rigorous, but maybe, like trusted. **So how can we create a more expansive idea of this value system and of impact that is also something that can be trusted?** I think some of that comes with that sharing of the resources of knowledge as well. But also, I just wanted to stay on impact for a moment, because the workshop that we're going to be holding on Wednesday is going to be about **where does this research land? Where do we want it to reach? What do we want the impact of these experiences to be?** And through this project there's been a lot of conversations about whether we want it to be able to go towards a kind of political change, like **policy change, structural change**, but also just like what people have been saying about the power of sharing with each other and listening with each other, and this collective learning that we're doing. So, I think that that is a basis to stand on, to go towards those structural changes. But I think the collective learning of not just lived experience, **but also the kind of practising together this stuff, I think, is really impactful within the people who are present…** And then the kind of research element of it thinking about the questions… How does it then carry? How do we disseminate it and share and invite people along the way?

FC: Sometimes I feel we speak a misleading language within academic research, using for example the word impact in a way that is actually not really bringing impact to people we are researching with. It feels sometimes like a performative set of actions that respond to meanings of words that actually do not mean what is needed. There is this language that is required in applications for funding, and we also use that language in order to understand each other, and then **the actions need to comply with that language but do not actually match what the meaning of those words could be.**

IB: I am not sure that writing journal articles that are getting published in academic journals is necessarily what members of the CWC would see as valuable really. But at the same time, if they want to be taken seriously in that academic world, that is the language the academic world speaks.

So yeah, it's a strange thing that I'm kind of pulling around quite a bit in my job, is like 'do I go down that route? Do I go down the open research route? Do I just ignore publishing? And I just say, as long as actually my stuff goes somewhere that I care about that matter? That's good?' It's a real sort of tug. It's a tug of war. I definitely feel that.

BS: I would have to say that actually **that dance happens within socially engaged art, social practice as well.** Of course, there's lots of projects that take place in the way that many artists want, but there's also where they have to engage in the gallery, maybe show in a way that is like a presentation, a gallery experience which is kind of like the same version of a journal, you know that **if we don't exhibit it in some sort of aesthetic visual way, then that project maybe doesn't have its value, or the next funding.** So, we also have these parameters that sometimes don't hold the same values as well. We have that struggle within visual art. It's interesting to have seen that mirrored in different ways. One thing I did want to ask is are these journals peer to peer reviewed for something like *Science, Nature*?

MI: So yeah, **generally journals in science are all peer reviewed.** The idea is that we submit an article like a manuscript which is usually meant to be blind to the reviewers, so you don't get your name on it or anything. **Usually, it goes to 2 or 3 peer reviewers**, they're usually professors or postdocs in some university doing vaguely similar things. They provide comments, and they can recommend 'yes, publish it without corrections or with minor corrections', or 'we don't want to see it ever again, please take it away.' That tends to be how it works. There are some different versions of that. There are some open access journals like Wellcome Open Research where, instead of being blind reviewers, you kind of get community-based reviews. So, someone can basically sign up to be a reviewer for that particular article, and then disclose their personal details. But the journal kind of aggregates all the recommendations, so that it may get published depending on what 10 people think, and those can be 10 completely different people who may have an interest in only one particular aspect of the study. You tend not to submit to non-peer reviewed journals. There are some, but we tend not to because they're not reputable in the same way. So, yes, there are different models…

BS: It made me think a little bit about Wikipedia. I don't really know so much about it, but I thought that that could be interesting. I would love to be part of a further conversation if it does happen. Really great to talk with you all.

JT: I just wanted to say thank you, Matthew, for your question. I think that empowerment, power is a really important thing to consider. I feel like within the structures that we live in we don't have very much power in many, many ways. **So, understanding where our power is, and building and creating collective power is so important in any area that we work in, whether that's within the arts, within research, within politics, within schools, and anywhere we work, wherever we can seek out and multiply and grow together our power, I think, is really important.** And I want to say a massive thank you for this conversation to all of you, really, and to Federica for framing and setting it up and for doing the work of making it research in its own way. Thank you.

IB: Thank you so much for the conversation and for this project, it's been really good.

MI: Thank you very much. Really interesting conversation. And yes, I'd be happy to talk more about this and about empowerment. Let's keep it going.

Mental Health: Imagining Beyond Research Group
consisted of Community Wellbeing Collective Members:

Alan Gordan, Bobby Sayers, Dalvina Kerr, Federica
Cologna, Jogob Sarr, Josie Tothill, Maryanne Jacobs,
Rumilla, RHM, Sarah Norman.

In close collaboration with Iona Beange, Knowledge
Exchange Officer at the University of Edinburgh.

Publication design and layout Bobby Sayers.
Cover design Maryanne Jacobs.

www.watchthisspace.online

"Working with the CWC researchers was inspiring. I realised that community driven research could develop immediate local benefits whilst providing insights for the direction of academic research. It is so important to support and learn from such projects and hear from a diverse group of individuals determined to support their community."

**Pippa Thomson, Lecturer and Researcher in
Psychiatric Genetics and Biology at
the University of Edinburgh**