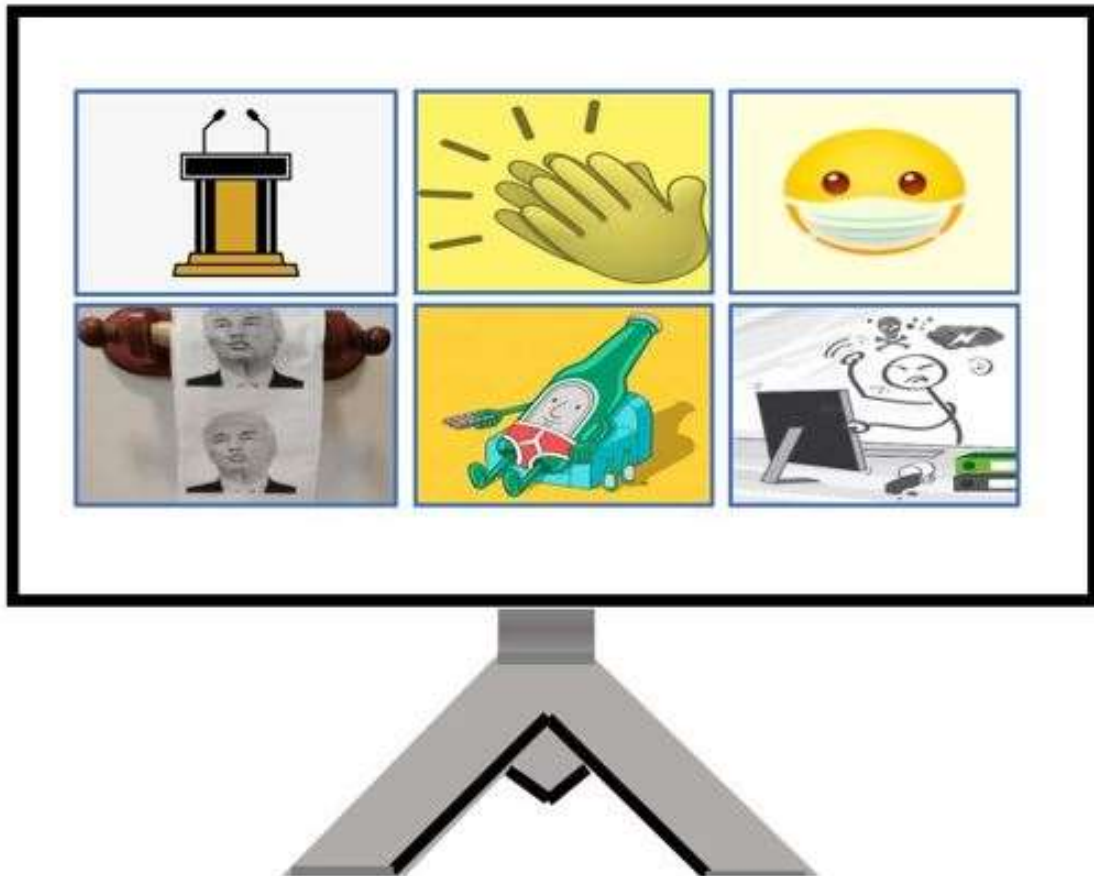


OUR LOCKDOWN EXPERIENCE 'Virtually' the People's Conference 2020

CAPS
independent
advocacy



How people across Lothian
with lived experience of mental health
issues have experienced
Covid-19 and the lockdown

Lothian Voices and The People's Conference

The People's Conference is an event for people with lived experience of mental health issues. It is planned by the Lothian Voices steering group, a collective advocacy group of people with lived experience of mental health issues, supported by CAPS Independent Advocacy.

The Steering Group

A key part of the People's Conference is how it happens. As well as being a platform for people to have their voice heard on the date of the conference, the process of planning the format of the event and the follow up are all ways in themselves for people to be involved, empowered and have a voice.

The Conference 2020

This year's conference was planned and attended over Zoom. This presented our steering group with several challenges. Deciding on the topic of 'Experiences of lockdown' came quite quickly as it was recognised that during this year this was a focus of everybody's life and that people with their own experience of mental health had lots to say on the unique factors that had affected them.

One of the biggest decisions the group made was around the format of the conference and how we could make it feel like the 'People's Conference'. There was a shared agreement that the identity of this event had become as important as the event itself.

The questions the group asked themselves were:

- How could we emulate the idea of group discussions?
- How would we ensure that creativity was a part of the day?
- How long should it last, as online participation was far more tiring than in person?
- What would the topics for discussion on the day be?
- How could we make people feel involved and connected?
- How could we make people feel safe?

One idea that developed quickly was the idea of having some kind of resource pack that could be sent to participants before the event. This was something that the group felt was a good way to help make people feel involved and at the same time allow us to provide creative resources without having to ask people to source their own items to take part in activities.

Lots of chat about how this could be done safely led us to produce a list of items that we would include;

- A pen
- A pencil
- A notepad
- 2 blank paper face masks for a 'then and now' feelings activity
- Badge making kit
- Blank card
- A fidget toy
- Goodies! Biscuits/teabags/sweeties



The group spent time researching 'break out rooms' and practicing how this worked and what would be needed to make it a positive experience that was easy to access.

We talked about the format of the event and decided that a half day would be enough for an online event and this led the group to think about what topics we could discuss and how we would capture people's thoughts on the day.

Another new experience for people was using 'whiteboards' on Zoom and the group spent time deciding how this could be interactive and creative. We decided on using the whiteboards to create mind maps. While this ticked some of the boxes, we also soon realised having enough facilitators would also be key.

The group agreed that 2 facilitators per room would mean that people could feel that they had the opportunity to just speak if that was what worked for them with one facilitator taking notes, whilst those who wished to interact could contribute to the other facilitator building up the mind map.

CAPS as an organisation made the decision not to record any of our Zoom sessions to ensure the privacy of our participants in accordance with our privacy policy. People told us that this was important to them and that it allowed them to participate in a way that made them feel safe to contribute in the way they wanted to and was in keeping with the spirit of the People's Conference.

The discussion on what elements of lockdown we should include for discussion on the day led the group to come up with 6 topics:

- Access to services
- Championing the positives
- Isolation
- Safety
- Resilience
- Motivation and Boredom

These topics came out of discussions with the group around what lockdown had been like for them. Several people in the group spoke about how the imposed isolation of lockdown was not that different from experiences they had lived through, or were living through, because of their mental health issues.

Members of the group also told us that groups being available online had been positive for them because their physical health meant that they were often unable to travel to join in with physical group meetings.

The group had lots of fun designing the poster for this year's conference and decided to follow the theme of our digital environment. You can see the results of what the resounding images of lockdown were for people on the front page of this report!

On the day

28 people attended the conference on the day. At the start of the conference we invited people to share the badges that they made before the event. There was a wonderful mix of colourful, creative offerings from participants and it was a lovely way to begin the conference.

The group asked Graham Morgan, Engagement & Participation Officer (Lived experience) with the Mental Welfare Commission for Scotland, to open the conference feeding back on the work they have been doing around Scotland to find out what people's experience of lockdown had been.

There were 3 topics discussed in the first breakout session - Safety, Access to Services and Resilience and the other 3 in the second session – Isolation, Motivation & Boredom and Championing the Positives.

In between the breakout sessions we made sure that there were plenty of opportunities to break from the conference and top up on tea and coffee but we also invited people to stay in the virtual main room to hear an extract of 'Plague Year' read by James Carter and a poem read by Samantha McIntyre that resonated with her own experiences of lockdown.

Our icebreaker activity after lunch brought a few laughs as we invited people to use the face masks that we had provided to show us what their expression had been at the start of lockdown and what it was now!

We used the “polls” option to gather feedback on people’s experience of the event and got very positive feedback on how included people had felt and that the pace and structure of the day had felt right and that people had enjoyed the opportunity to have their voices heard on how the lockdown had affected them.

Over the following pages we will look in detail at the feedback from the discussions on the day, however the **key themes** that came out of the day were:

- People felt abandoned by services and there was a large amount of uncertainty;
- There was a sense of unpreparedness and lack of innovation in statutory services;
- Information over the course of the lockdown was confusing and difficult to wade through;
- People were concerned about putting pressure on the NHS. There were confusing messages about who and when to contact services coming from government, creating anxiety;
- Online communication is welcomed but the need for 1-1 contact is needed and missed;
- New sense of community was experienced through different interactions over lockdown;
- The difference between adaptability and resilience needs to be recognised by services moving forward - one does not equal the other.

SAFETY



People told us that during lockdown there had been several different experiences that had made them feel particularly unsafe. One of the most difficult things for people was the lack of clarity around what the rules were at any given time.

People spoke about this in a variety of ways, they talked about police officers seeming very intimidating, but also the idea of neighbours and people in the street being judgemental over what they were doing.

Not knowing where to reach out to was another factor that made people feel very unsafe. They told us that they didn't know if they could contact their GP and others told us about abrupt and unhelpful communication with mental health services when they were unwell.

Worrying about family and friends was a huge source of concern for people, both in not being able to see people in person and not knowing if their supports were in place for elderly or unwell relatives. People told us about the conflict of wanting to follow the rules but at the same time being really worried about friends and family.

There were also lots of comments about how unsafe it felt now that lockdown was easing with people who were not following rules about gathering in large groups and wearing face masks. Public transport was mentioned as being particularly difficult and people told us that it made them angry that people were not paying attention and this made them feel like the crisis would never be over and that they feared this would mean that lockdown would be reinstated, which was a really difficult concept for lots of people.

There were several comments however from people who spoke about how the slowing down of life had been a real positive for them and that not having the pressure of going to

appointments had been a bonus for them. The peace and quiet of a reduction in hustle and bustle had been very welcome.

There were comments about the care and support that some people had received from neighbours and supports and how this had helped to make people feel safer during lockdown. Others told us how they had received really positive experiences where their consultant had made a considered effort to keep in touch and helped to rearrange prescriptions for them and this had made them feel really safe.

People wanted us to know however that neighbour experiences had not been universally good.

"I was worried about my parents. They are frail. I had to encourage them to get information about shielding. We had to do more caring than normal. The support wasn't in place. That meant that we had more interaction than we were meant to"

"I felt physically safe. It was lovely having peace and quiet."

"travelling on the bus, I get agitated by people not wearing masks."

"It felt sinister. People giving you into trouble. My neighbour went out and got into trouble from a policewoman, saying, he shouldn't be on his phone. He wasn't well when he went out and was a state when he came back. You didn't know if you were going to be told off just for going out."

"For me, one of the problems we are getting the rules for England on the news.. then try to listen to the Scottish briefing. It's easy to get mixed up....They don't then say how it's different in Scotland."

"Good neighbours – helpful and contribute to safe feeling in community because of lockdown"

"I wasn't sure if I could speak my own doctor during the lockdown....Then was told, oh no you can speak to your usual doctor no problem. I didn't know I could. My mental health was really bad. So then I spoke to her every week."

ACCESS TO SERVICES



Access to services proved, perhaps unsurprisingly, to be one of the most vibrant conversations of the day.

People told us that they had felt dismissed and abandoned by many of the statutory services. We heard examples of people who had been in treatment and had been cut off, not hearing from their service for months at a time. Also, we heard about experiences of people becoming unwell with their mental health and having extremely distressing responses from emergency services.

Not being able to get in contact with services was another issue that people spoke about, people not answering phones or up to date information about what the service was doing during lockdown caused people high levels of anxiety and meant that their mental health got worse.

One of the most highlighted things when talking about access to services was the apparent assumption of people's capacity to access and use phone and online methods to receive support.

Apart from the fact that the lockdown seemed to show how glaringly digitally unprepared many services were, particularly statutory services, attempts made to offer alternatives to those who found this method of communication difficult were very limited. People spoke about how letters for appointments had not indicated that they would be by phone and they had worked up to leaving the house and not found out till the last minute that it was by phone and how this had made them very disorientated.

People told us how difficult it was that many of the groups that they accessed had stopped and that there did not seem to have been any attempt to put anything else in place and that not only were these the only 'services' that were on offer to them, but that this had increased their sense of isolation.

Some people were able to tell us about some positive experiences that they had had around access to several third sector organisations. People told us that CAPS and Vocal had both been very helpful and that accessing crisis lines like Breathing Space had been really helpful.

Several people had received good service from their GP practice and that they felt the service had adapted well to the situation. Others had positive experiences with their chemists and people told us about good experiences with volunteers who had supported them.

"When I wasn't well I went on a manic high. I was up all night. I called the emergency team at Royal Ed. One nurse said - you can't just call up here and use it like a counselling services. I was appalled. It's not peoples fault they are not well"

"Chemists were great, if you ring them and they know you, and able to give you what you needed"

"Drop in's have stopped, mental health chaplaincy stopped. Missing that a lot".

"Lack of clarity if services are in person or on the phone – lack of clarity and psychologically preparing yourself to go out for 2 days but then it's a phone call, should have been quite easy to mention on a letter, not cost many more resources"

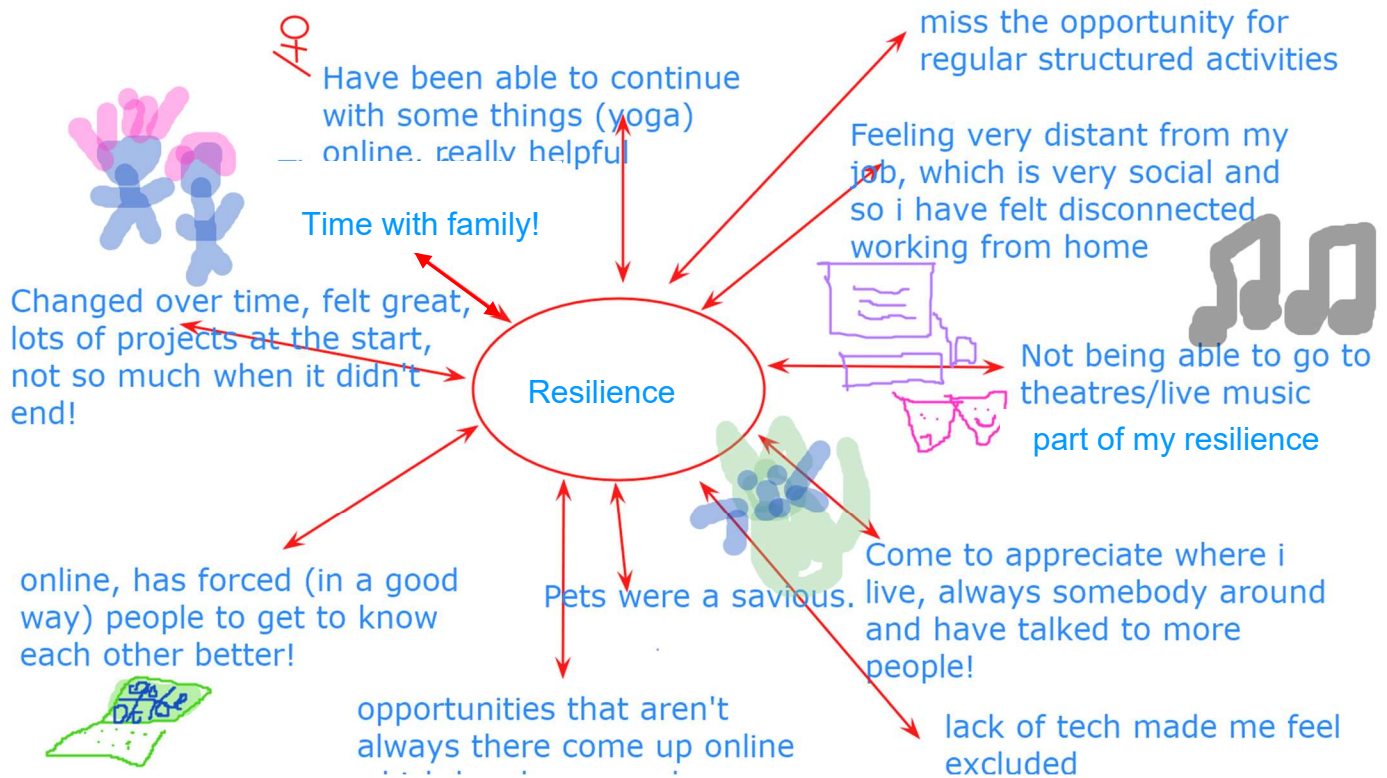
"VOCAL were doing really well. I'm on their books. You get a decent human being on the phone. They were a beacon actually"

"I used to see my psychiatrist every 3 weeks. I have had no appointments since lockdown and they haven't contacted me".

"Assumptions of what people can do or not, e.g. not using smartphones, government not taking into account different kinds of ways of accessing services, e.g. online shopping"

"Volunteers contributed a lot, enjoying their support shopping and cooking meals"

RESILIENCE



There were mixed feelings about the concept of resilience, and it was recognised that this meant very different things to different people.

People told us that it has been a very moveable feast over the course of lockdown. Some people felt a sense of 'hunkering down' at the start of lockdown and used the opportunity to try new things, expanding their knowledge of online communications, appreciating neighbours that they had previously not spoken to – making new connections, and appreciating hobbies like yoga, reading and fitness. Others told us that being isolated without being ill was a pleasant change!

However, many people told us that this had been more difficult to maintain as time went on and several people spoke about feeling very excluded because of their lack of digital access or lack of confidence to engage in this way.

Others told us that they had felt very disconnected working from home and that their resilience came from their social connections with work colleagues. People also spoke about the hobbies that kept them feeling engaged and resilient were now all at a standstill, like theatre and live music events.

Another thing that emerged as a common theme for people was the lack of resilience from services. Several people commented on how long it had taken some services to find other ways of connecting with people and that even when they had there was still a sense of no flexibility, from only phone contact, to limited platforms (Zoom/Teams/Skype) that services were *allowed* to use and this made it even more complicated for people to adapt once they had become comfortable with one way – it felt obstructive.

"At the beginning I felt there was things I should do. But by the time I got to reading all the time I thought I don't need to worry about doing the right thing and could enjoy myself for a wee while."

"Resilience of services: not everyone can access online. Smaller organisations adapting faster than larger organisations."

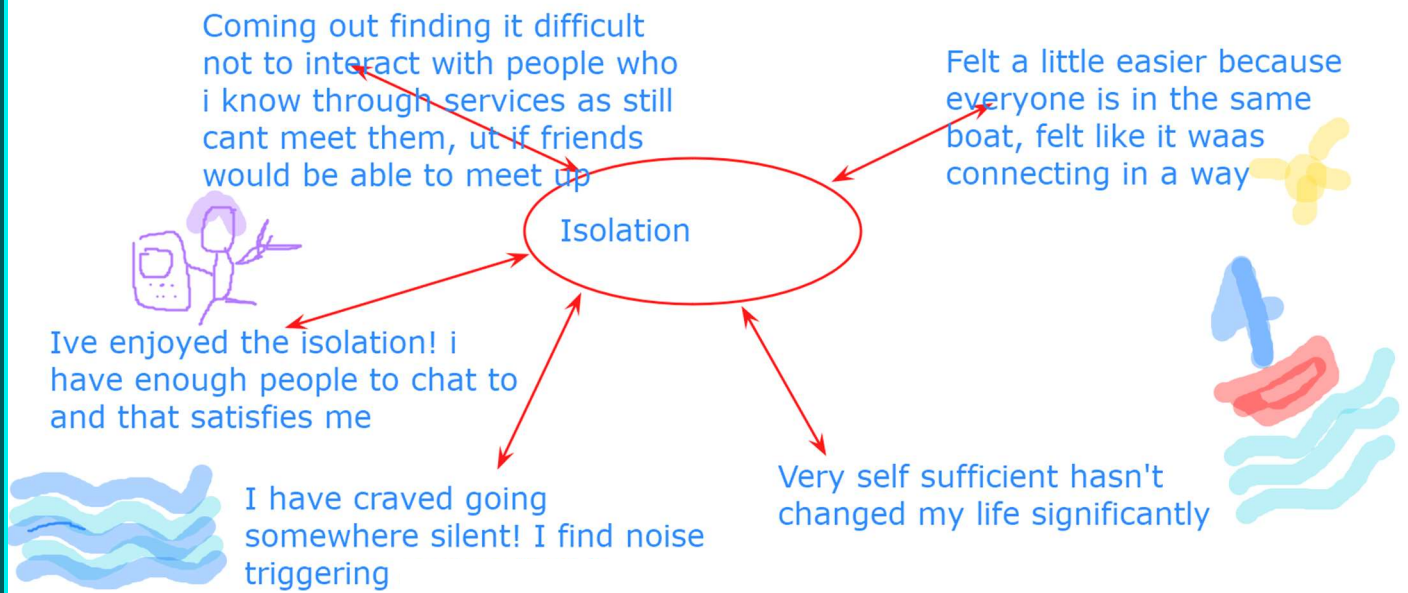
"Being in isolation but not being ill being enjoyable experience"

"Not being able to go to theatre or live music, big part of my life and keeps me happy. Not good for my resilience not being able to go."

"I've been lucky. Yoga at royal ed. NHS wouldn't let teacher keep it going on zoom, but she found another way. MH nurse called me every week to see if I was OK. It was really nice. It wasn't; something she had to do, but they did and it was really nice"

"Different kind of stress – so difficult to handle COVID as 'background noise'"

ISOLATION



The discussions around isolation were split in a similar fashion to that of resilience.

Many people spoke about the advantages of a less busy feeling and once again talked about having previously adapted to a more solitary life due to their mental health. Others told us that due to physical health issues having online meetings has dramatically reduced their isolation as these options hadn't been there before and they had often not been able to join in. However much of the conversation centred around the constant changing of the environment.

People spoke about how they are unsure and fearful of what the new 'normal' is now and concerns over how communication will feel with everyone wearing masks and some people told us that this could be quite triggering for them having experiences of trauma.

People they told us they were worried that this long period of isolation would make it more difficult for them to resume connections in the way they had before and that planning for more communication now was a source of anxiety for them.

Some people told us again that confusion over the messages that were coming out about what was allowed and what was not was making it very difficult to tear away from the sense of isolation. Fear of judgement or breaking the rules was keeping them isolated and others told us how the changing system meant that they were able to see some people – neighbours etc, but not others and that as their friends were often part of groups like collective advocacy that were not yet able to meet in person, this felt artificial.

"I found it difficult, I'm a social person. I'm usually out every day. It was getting to the stage I worried that I'm going to end up with agoraphobia....."

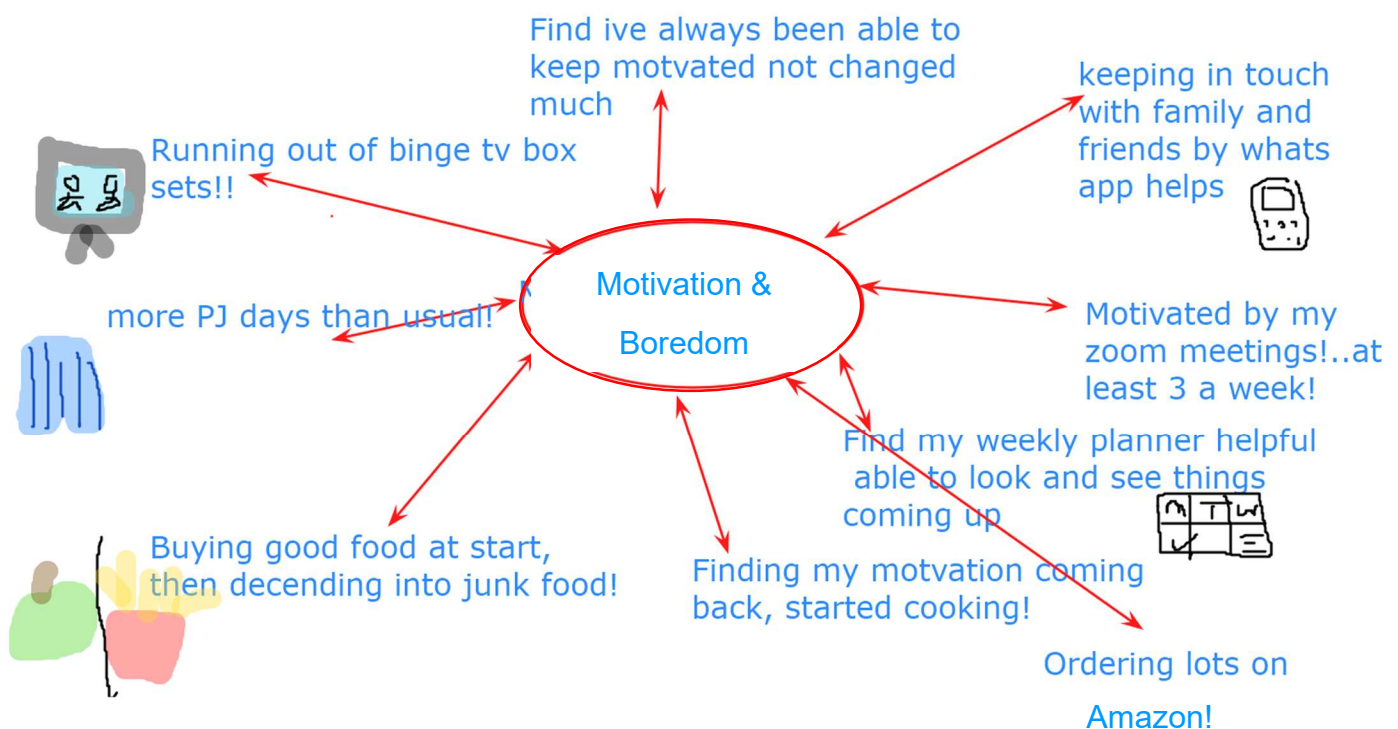
"Because of trauma symptoms being activated by noisy neighbours I've craved somewhere quiet."

"Experience of isolation before lockdown was more because was already housebound and couldn't access meetings when they were face to face So is finding accessing online meetings great, as there wasn't this opportunity before"

"Right now, I'm worried about the impact of masks and how people are communicating. I was wearing them in March and started to get panics and anxiety and people don't realise this can happen. People are judging"

"I quite like being isolated and doing things on my own. So it's been helpful. But things have changed now and people want to chat, and I'm not able to plan for that. I like chatting while doing activities with people and my activities have disappeared."

MOTIVATION & BOREDOM



Much of the conversations on motivation and boredom surrounded how a largely online environment had affected this. Some people told us that online meetings with services and groups had been lifesaving and educational but there was a universal agreement that this type of communicating was also quite exhausting and a completely new way to interact, introduced at a fast pace and that more consideration over how this happened would have been useful.

Other ways that an online life had affected people's motivation were longer periods of time watching box sets, ordering items from shopping sites and spending time on social media. Whilst there was a recognition that these things were useful people also told us that they were very distracting and people found it difficult to detach from them, meaning that other things, like household tasks etc were neglected.

People spoke of the 'try something new!' phenomenon being rather exhausting and rather than encouraging motivation it felt overwhelming.

People noted that negative habits had crept in the longer the lockdown had gone on, more PJ days, increasing alcohol and junk food and that again the length of time of lockdown had been a big influence on this.

People did tell us that maintaining routines had been really helpful throughout lockdown and maintaining a daily planner had been really grounding.

"Now, I'm an alcer-holic, I am in love with Elizabeth Alcer on BBC Radio 4!"

"I'm a Facebook addict, I confess. Sometimes I get good information and contact with people, but it pulls you in and affects my motivation to do good things, like the washing up or getting out of the house. Too long has gone by and I haven't done them."

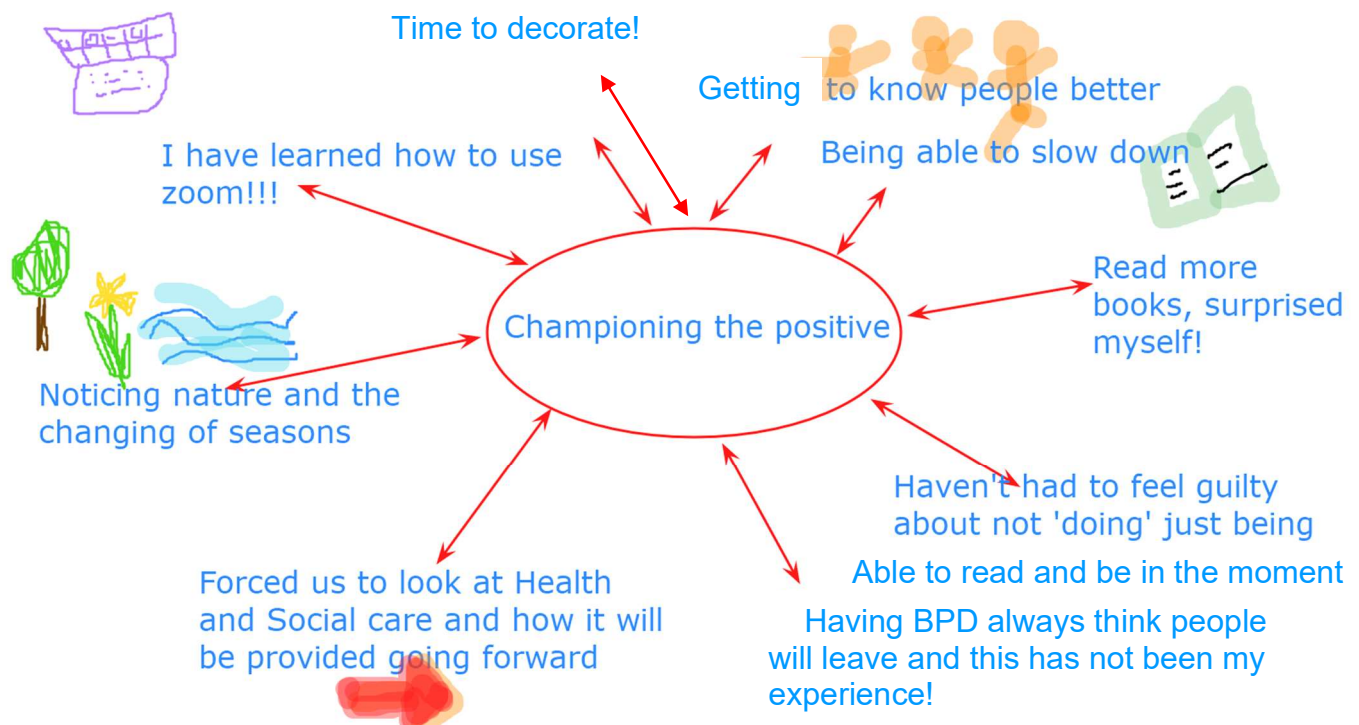
"Overwhelmed speaking to people all the time virtually"

"Having a regular routine even if indoors the whole time really helpful "

"I'm worn out with new things happening. It's good but also really tiring. It's mainly online things. It's hard to get to do all these things usually. Before you didn't have the opportunities. Now the specialists are all locked down too so they put them online. There's more opportunities."

"Having a lot of different disabilities feeling frustrated stuck in"

CHAMPIONING THE POSITIVES



When our groups spoke about the positives that had arisen from this situation there were a few key things that people recognised as having been really good. Connecting with others, an increased awareness in society for what life may have been like for many people in society without lockdown and innovation for connecting and communicating were highlighted as some of things that lockdown had brought.

People told us that they had been in contact with family and friends more often than they normally would and others spoke about the re-emergence of more organic groups getting together informally which felt like a really encouraging move.

There were several conversations about the creative ways that services had found to continue things like online choirs and exercise classes. And that working from home had meant that people had been able to have things like 'pets at work' which was very therapeutic for their mental health.

However there was also a sense of frustration at the fact that people with lived experience had been asking for these types of choices for many years and been told that they were not possible, and real sense that these kinds of options should be available going forward and not just disregarded when lockdown eases.

People did want to note in this section that there is a real sense of 'absent friends' during the whole lockdown experience. Whilst many of the things that have emerged have been positive for people to connect there are also people that have fallen off the grid and not been able to get involved and people wanted to ensure that this is not missed in evaluation of this time.

People spoke about the increased sense of community and appreciation for services that are not usually championed, such as retail staff, as being very heartening, hearing the clap for carers was a unifying experience for some.

“Everyone’s had to be isolated people have greater sympathy, e.g. for people who are disabled or who have different barriers”

“I think a lot of people are using different services and people are more open to video conferencing. I think that’s good for people. Like the educational programmes, are also for people who live further away.... it’s more inclusive now for people because it’s online.”

“Absent friends – people who are not able to join in zoom, haven’t seen them.”

“I hope there’s going to be more informal organising of things. I used to years ago and people I used to do it with have been getting back in touch. I would love it if more people were doing it. Like trading without money and peer support. I don’t think it’s just me, but people have been valuing nature, fresh airs, gardens cycling and walking.”

“New routines or ways of pursuing interests online actually being busier than normal”

“Glaring hole in services for disabled people. Need to tell them about that – not just write a letter”

“I have been in touch with my relatives more now, every week. They are phoning me as well and we are trying to support each other.”

FEEDBACK FROM THE DAY

People told us that they found the conference easy to register for and that the information they received before the event was clear and helpful.

One of the things that people told us was that whilst they appreciated the intention behind the resource pack, they had not fully appreciated what the intention of this was in relation to how it would be used on the day, which has been a really good learning point for us when explaining how we can and will use digital technology in combination with hardcopy resources and how we can make this accessible for everybody.

People let us know that during the breakout rooms they found the discussions relevant and that they could contribute easily.

People were happy with the length of the conference and told us that they didn't feel that it dragged at any point and that the breaks were pitched at the right times during the event.

The feedback we got suggested that people felt that although there was a certain amount of exposure in the breakout rooms, they felt that was ok and managed well.

"Yes, the CAPS staff were very friendly and easy to identify. Everyone was extremely nice and polite and well-behaved. In particular I would say the intellectual level in the breakout room was pitched quite high but I found that quite welcome"

"It was a wonderful pack to receive. I enjoyed my biscuits at the event. I gave my fidget toy to my two-year old grandson but unfortunately he was too young to enjoy it as I had!"

"I love what you do and would like to see more"

"I think I would say it all worked extremely well."

"I was very impressed by the standard of the discussion in our break-out room. I felt able and was glad to contribute".

A JOURNAL OF THE PLAGUE YEAR – James Carter reading at ‘Virtually The People’s Conference 2020

The Great Plague of London ravaged the capital from 1665 to 1666. City records indicate that some 68,596 people died during the epidemic, though the actual number of deaths is suspected to have exceeded 100,000 out of a total population estimated at 460,000. The outbreak was caused by *Yersinia Pestis*, the bacterium associated with other plague outbreaks before and since the Great Plague of London.

Daniel Defoe, the author of *“Robinson Crusoe”*, published his *“Journal of the Plague Year”*, an account of the Great Plague of London, in 1722, some 56 years after the history it records. Defoe was only five years old at the time of the Plague but in the book he identifies specific neighbourhoods, streets, and even houses in which the events took place. The book also provides self-contradictory adulation and equal amounts of condemnation of the authorities though it is clear to me that in many ways the Great Plague was better handled than COVID-19 in our own day.

For example, wardens were appointed to attend every affected household, a warden by day and a warden by night. And Defoe says: “The concern ... of the magistrates for the supplying such poor families as were infected – I say, supplying them with necessaries, as well physic [i.e. medicine] as food – was very great, and in which they did not content themselves with giving the necessary orders to the officers appointed, but the aldermen [i.e. town councillors] in person, and on horseback, frequently rode to such houses and caused the people to be asked at their windows whether they were duly attended or not...” Can you imagine today's politicians showing this level of care to common people?

The Journal's most famous passage humorously tells of the poor people's superstitiously keeping off of the plague “wearing charms, philtres [Old English for “face-masks”], exorcisms, amulets, ...with crossings, signs of the zodiac, papers tied up with so many knots, and certain words or figures written on them, as particularly the word Abracadabra ... thus:-

ABRACADABRA

ABRACADABR

ABRADADAB

ABRACADA

ABRACAD

ABRACA

ABRAC

ABRA

ABR

AB

A”

Nowadays, instead, people might sing the pop-song “Abra-abracadabra!/Wish I could reach out 'n grab ya!” !!!!!!!!!!!!!

James Carter

POEM (Unknown author) – Read by Samantha McIntyre at ‘Virtually’ The People’s Conference 2020

I found this poem on Pinterest at the beginning of lock down. I was looking for something relevant to send in to the ‘Outlook’ online newsletter. I thought it was relevant to what many people were feeling at that time. I sent it on to family and friends as well. The feedback was great. People identified with it, and I was thrilled that the feedback at the end of my reading at the end of the conference was just as positive!

We’re all wayfaring travellers,
Trudging down our separate roads
Hoping, wishing, praying,
Someone will come to share our load,
There’s sunburn on our shoulders,
And blisters on our feet,
We brave the wildest blizzards,
And the scorching summer heat,
Sometimes we find somebody,
Who is going our way too,
And while they walk beside us,
The sky seems a bit more blue,
But all roads twist and turn,
And when you reach the intersection,
It’s likely life will take them,
In the opposite direction,
But don’t give up on hoping,
When your road is a dead end,
It’s likely that you’ll find,
It’s only just a bend,
And though other’s roads are different,
It doesn’t mean it’s wrong,
So pick yourself back up again,
And just keep trudging on.

Next Steps



This report will be launched at CAPS AGM on the 20th of November 2020.

Our steering group are planning to organise a follow up Zoom event that will look at all the report and invite people that the group believe should hear the information contained in it, from local Health and Social Care Partnership leaders and other relevant services to Scottish and National MP's.

CAPS will ensure that this report is distributed to everybody who registered for the event.

CAPS will publicise this report on our website through our networks and will continue to present it at other relevant forums.

One of the groups' hopes moving forward from this event is to reach out wider to new audiences and increase the diversity of people that are reached with these messages.





Acknowledgements

CAPS would like to thank everyone in the Lothian Voices steering group who was involved in the planning, collaboration and organisation of this year's, very different, but equally as enjoyable People's Conference!

For all those who participated in the conference CAPS would like to thank you for your time. It was great to see so many people attending and joining in with all our virtual activities.

Thanks to Graham Morgan for taking the time to open the conference with the wealth of information about people's experiences throughout the lockdown gathered from across the country through his work with the Mental Welfare Commission. If people would like to find out more about the work of the Mental Welfare Commission you can check their website at: <https://www.mwcscot.org.uk>

And of course, a huge thank you to both Samantha McIntyre and James Carter for their thoughtful readings on the day.

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