

FORGOTTEN? Montal Hoalth Communication

Mental Health Care and Treatment During the Coronavirus Pandemic

Research Report

"You just feel like a forgotten child, you know? You're just like a lost child in the corner that somebody's forgot about". Gus, interviewee



Foreword

The pandemic has changed how we all have lived our lives in ways we could not have imagined.

We have experienced restrictions on social interaction, travel, visiting friends and family, and going to work. The ways in which we receive health care and support have also changed radically. At SAMH, we were aware that the mental health of everyone in Scotland was likely to be affected, with people already living with mental health problems certain to be one of the hardest hit groups.

We commissioned this research to understand how people's experience of mental health care and treatment changed during the pandemic. What we learned can help us as we shape Scotland's recovery: we must ensure that mental health services are available when they are needed, and this will require significant effort and investment.

We are grateful to everyone who took part in this research. By sharing their experiences at this uniquely difficult time, they will help everyone involved in mental health understand what must now be done. My particular thanks to those who took part in qualitative interviews, which offer a depth and richness of detail which is truly valuable.

The findings in this report make clear that mental health services must now be a national priority. At SAMH, we stand ready to assist in this, as we begin our recovery from this truly extraordinary time.

Billy Watson

Chief Executive, SAMH

SUMMARY OF FINDINGS AND CONCLUSIONS

The coronavirus pandemic has hit people with preexisting mental health problems hard. Our research has shown that systemic changes to the delivery of mental health care and treatment have resulted in increased feelings of mental ill health and affected people's ability to cope.

The move away from face to face mental health support has brought significant challenges to people with mental health problems. For many, these are felt to undermine the nature and quality of patient-professional communications, and negatively affect the treatment process and therapeutic benefits. It is therefore essential that there is a return to face to face mental health support as soon as it is safe to do so.

At SAMH we would like to see this commitment to face to face, in person support firmly embedded in future iterations of the Coronavirus Mental Health - Transition and Recovery plan¹, and in any refresh of the Mental Health Strategy.² While digital services certainly have a place in mental health care and treatment, these should not become the default.

Importantly, the research highlights the importance of consistent support for people with mental health problems. This emphasises that the difficulties that have emerged are due to systemic changes to the way support is being delivered, rather than the personal relationship between practitioners and people receiving support. Receiving regular care and treatment from practitioners known to respondents was seen to be helpful and effective. Conversely, disrupted, reduced or inconsistent care and treatment delivered by practitioners without a preexisting relationship with respondents was experienced as challenging and at times distressing and damaging to participants' mental health.

On a practical level, changes in the methods that people can use to access mental health support were generally challenging. This included difficulties in accessing GP support due to perceived gatekeeping behaviours by surgery staff, the need for telephone call-backs from GPs and a lack of privacy for telephone or video consultations. Other problems included a reliance on the signposting of telephone support as the only means to access support in a crisis and a reduction in support and communication from multi-disciplinary teams.

The pandemic itself has had a profound impact on people's confidence in accessing support. The research showed that there is a perception that mental health has not been prioritised by either the NHS or Scottish Government. People reported feeling like a burden and anxious about adding to the pressure of the health service by asking for help and support. It is imperative that more is done to ensure that needs are met and that people experiencing mental health problems, including crisis and suicidal thoughts, feel confident in accessing health services for the support they need and deserve.

The coronavirus pandemic was not the sole cause of the mental health crisis in Scotland. Mental health services were already struggling prior to the pandemic. We must now see investment in psychological wellbeing support, accessible help for children and young people and long-term plans on suicide prevention, to ensure we can rebuild Scotland's mental health.

CONTEXT -CORONAVIRUS IN SCOTLAND

The first coronavirus case was confirmed in Scotland on 2 March 2020.³ Following an increase in cases, Scotland entered the first national lockdown on 23 March.⁴ The lockdown included a legal 'stay at home' restriction which included the closing of non-essential shops and restrictions on social gathering.

The national lockdown restrictions began to be eased on 29 May 2020 with limited outdoors social gatherings allowed.⁵ Further easing of restrictions were introduced throughout the summer of 2020 with non-essential shops and schools reopened. However, a new local system of restrictions was introduced in November 2020, with a return to a full national lockdown for mainland Scotland introduced on 26 December 2020.⁶

CORONAVIRUS -MENTAL HEALTH CARE AND TREATMENT

The lockdowns resulted in significant changes to how mental health care and treatment was delivered in Scotland. Community services, including support from GPs, had to be delivered over the phone or by online video call. Referrals to mental health services including Child and Adolescent Mental Health Services (CAMHS) and adult psychological therapies also dropped substantially.

ABOUT THIS RESEARCH

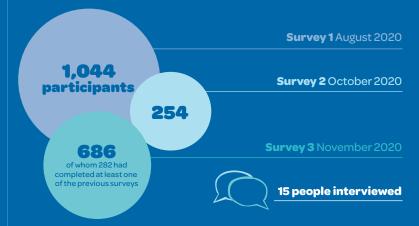
This report summarises key findings from a longitudinal research project undertaken by Jacki Gordon on behalf of SAMH. The two key research questions were:

- In what ways has the treatment and care that people in Scotland receive for their mental health changed due to the coronavirus pandemic?
- How have these changes been experienced by people in receipt of care and treatment, and what effect have changes had on their mental health?

Over 1,000 people took part in the research, through three surveys which ran in August, October and November 2020, and a series of 15 interviews which took place between August and December.

To take part people needed to: live in Scotland; be over the age of 16; and have been referred to, or received treatment from a professional (such as a GP), organisation or service for their mental health at any time since January 2019.

Only those people who completed the first survey were invited to take part in the second. However, as the third survey took place at a time of increasing coronavirus cases and the reintroduction of restrictions, the third round of the survey was opened to new respondents, as well as previous participants. The total participant numbers were



The research was self-selecting and so is not necessarily representative of the wider population.

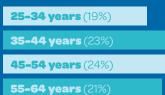
The three surveys involved 'routing', meaning that depending on a respondents answer to a particular question, they may bypass another. Also some participants have chosen to not answer all the questions in the surveys. As such, the number of respondents to each question vary. Where percentages are provided in this report, they are a percentage of the number of people who answered that particular question, rather than a percentage of people taking part in the survey.

DEMOGRAPHICS



Across the three surveys, the vast majority (80%) of participants identified as female

The age breakdown was as follows:



Virtually all (99%) identified as white.

There were respondents from all health boards, with the exception of Orkney.

Respondents experienced a wide range of mental health conditions, with around three quarters indicating:

Anxiety/panic disorder	(74 -78%)*
Depression	(72 - 76%)*

% range varies depending on the survey

Over half (55%) of respondents from the first survey had recent contact with a Community Mental Health Team (CMHT), indicating that they were likely to be living with severe and enduring mental health problems.

The fifteen interviews were selected to provide a mix in terms of age, sex, mental health conditions, and health board area. In addition, interviewees were selected to achieve a range in terms of treatment history e.g. treatment by GP only, under the care of a psychologist etc. The respondent and interview names have been changed to protect anonymity.



KEY FINDINGS

- There have been very positive examples of participants receiving support from individuals

 GPs, specialists and via third sector employees and peers.
- The pandemic has introduced systemic changes and associated challenges in accessing and using services.
- Perceptions and experiences of services prioritising those at highest risk have created uncertainties and discontent regarding treatment availability and options.
- The move away from in-person consultations has brought significant challenges. For many, these are felt to undermine the nature and quality of patientprofessional communications, and negatively impact on the treatment process and therapeutic benefits.
- Professional consistency and continuity were highly valued. Where this had not been participants' experience, this was a source of discontent.

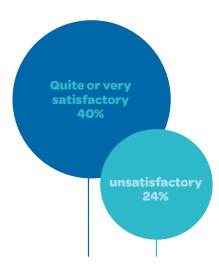
- There was considerable dissatisfaction with newly introduced procedures that involve phoning up the GP surgery to make a telephone appointment without having the choice of which GP would call back.
- Changes in consultations' frequency, intensity and range have led to frustrations and dissatisfaction, with comments suggesting that the mental health and/or recovery process have been adversely affected.
- Levels of coping and self-reported mental health have deteriorated since, and over the course of, the pandemic.
- The pandemic itself, and changes in treatment/care have contributed to feelings of disempowerment and isolation.
- There were perceptions that services are thinly stretched, and that services need more capacity to respond to mental health needs.
- There were fears about mental health deteriorating, and whether there would be the support that would be needed.

Detailed Findings

ABSENCE OF FACE-TO-FACE SUPPORT

"The lack of face to face meetings - you're not gauging how people see you. I mean how do they know how I am? If they can't see me, they can't see if I've not washed or dressed for three or four days or five days. They cannae smell if I've not had a wash for a week. Do you know what I mean?"

[Barbara, interviewee]



Having consulations by phone about mental health

The most common theme affecting respondents' experience of accessing and receiving support was the widespread loss of face to face support from medical and social care practitioners. This issue was raised across all forms of support, including both primary care and specialist mental health care and treatment.

In our first survey, over four fifths (83%) of respondents told us their mental health support was now being delivered by telephone or online: over two thirds (72%) said their support was being delivered by phone.

The issue of a move to remote support was frequently mentioned in our first survey as the issue that mattered most to survey respondents. Examples from participants included:

"I cannot do Zoom, or voice calls due to anxiety".

[survey1respondent]

"Sessions did not feel as personal and being vulnerable was a lot more difficult." [survey1respondent]

"It's hard for them to get the right picture over the phone". [survey1respondent]

"Having to do it all through the phone. I get anxious talking on phone and struggle understanding/read things. Also not good with technology" [survey1respondent]

Our research asked participants their opinions on phone and online video support. For phone support the overwhelming majority – over two thirds (79%) - of respondents indicated that 'telephone consultations are better than nothing'. Despite this, about three quarters (76%) were of the view that 'face-to-face is better than simply talking on the phone'. A substantial minority of respondents – around a quarter (24%) – felt that having consultations [about their mental health] by phone was unsatisfactory. However, a higher number of participants, nearly 40%, felt that phone consultations were either quite satisfactory or very satisfactory.

There was more satisfaction with online video calls, with just over half (54%) of respondents feeling that consultations by video were either quite satisfactory or very satisfactory. Factors such as being able to see the practitioner, and therefore be better understood, was felt as beneficial in regards to video calls.

"I think just being able to see the counsellor's face, it was easier to connect with him and easier to kind of express how I was feeling and I think it was easier for him to kind of understand as well, and it just...yeah, it was helpful for like getting to know him as well and it wasn't just a voice, it was a face as well, and it made me feel like I could open up to him more, being able to see his face as well"

[Sally, interviewee]

Despite this, people had issues assessing or engaging with video consultations. About a fifth of respondents (21%) found it difficult to deal with the technical side of video consultations. Just over a third (36%) indicated that lack of privacy had been a problem for them (this is a higher percentage than was the case for telephone consultation).

"When you're sitting in your house and you're sitting talking, you're conscious of people coming in, like my son and his girlfriend come in and out of here, you're scared to say things. There's some things you don't want people to know". [Douglas, interviewee]

People who were already isolated due to lockdown restrictions and existing living arrangements described the loss of face to face interaction with practitioners as further contributing to feelings of loneliness and isolation.

"You need somebody there face to face that can see, that can reassure you ... you cannae do that on the phone, they can't give you that calming influence when they're on the phone".

[Douglas, Interviewee]

"I became a bit of a hermit of late ... I then started feeling nervous about being out and about, so the good thing that it was all done on the telephone meant [so] that you weren't going out and interacting and you were staying safe. But the negative part of that is you feel a little bit more isolated."

[Luke, interviewee]

"I think the fact that obviously therapy was only over the phone and I couldn't properly talk to someone, I felt a lot more alone, and especially because I spent a lot of time in my flat on my own I just kind of felt like I couldn't talk to anyone and that there was no one that could help me, and that was really difficult." [Sally, interviewee]

Other interviewees talked about the loss of physical cues including from body language – particularly in the case of telephone consultations. This manifested itself in a variety of ways, including the misinterpretation of silence during consultations:

"If you go to see somebody face to face, at least, you know, you sit there and you can say nothing. Although you're sitting there, you can't get the words out, and then you know, somebody will say 'ok, we'll talk about this' or 'we'll talk about that', and it makes you get the words out, but if you're at the end of a phone, somebody's going to think' oh there's nobody there' and they're just going to be like 'I'm going now'." [Patricia, interviewee] It was also felt that practitioners picking up on someone's mood or visual cues was very challenging during remote consultations:

"I think in face to face there's a lot more that can be communicated and not just necessarily verbally, kind of I know myself when I get anxious, I can kind of put on quite a kind of front when I'm talking. I've got quite a good persona of kind of covering it up. But...I always, like, clench my fists and I do that kind of stuff as well when I'm stressed and nervous. I think that kind of communication is missed on the telephone" [Susie, interviewee]

SUICIDE AND THE PANDEMIC

In all three surveys we asked participants if they had experienced thoughts about suicide, suicide attempts and self-harm. While results cannot be generalised across the Scottish population, we believe they provide an insight into suicidality among this group of people with mental health problems during the pandemic.

Our third survey found that over 70% of respondents had experienced at least one of the suicidality indicators listed above. More respondents experienced suicidal thoughts as the pandemic continued. In the third survey, just over half (52%) of participants reported thoughts of suicide in the six months prior to the pandemic, compared with just over 60% (62%) since the pandemic: an increase of 10%. The frequency of thoughts about suicide also increased, with a third of respondents indicating that they thought about suicide more often than before the pandemic. The reported rates from respondents regarding self-harm and suicide attempts prior to and since the pandemic did not change, suggesting it was suicidal thoughts rather than attempts which had increased.

It should be noted that as all the participants of the research had prior experience of mental health problems, some of them severe and enduring, it could be expected that they may experience higher levels of suicidal thoughts than the general population. The key point highlighted by the research however, is that these thoughts increased as the pandemic continued.

Case Study: Sam

Sam is a young man, aged between 25-34 who has been treated for anxiety and depression for around ten years.

He has experience of a wide range of services and support. When asked what three words describe how he feels about treatment or care since the pandemic, he responded 'neglected; pushed aside'.

"Neglected because throughout the entirety of lockdown, my mental health was already bad but there was several triggering events that worsened it, and I just felt like I was waiting over a month to even get like a call back from a mental health nurse. The only solution that I was getting offered was 'oh here, have some medication, we'll just up your medication' and there wasn't a support network at all ...on the whole I just felt very neglected, like I just felt like a digit, a number, rather than a person struggling.

"I just felt like with the GP I had at the time, he just was very nonchalant when I'd phone up and express how...like I'm really struggling and I don't have a direction or like a way to go to get help, he was like 'mmm, mmm' and then he'd be like 'ok listen Sam, I need to go now because I need to phone another patient' etc., and I just felt obviously you don't care, ...you're just ticking boxes."

Sam was not happy with this last GP's suggestion to increase his antidepressants. He felt 'fobbed off' by this. Sam felt that he was not moving forward, that he 'was going round in circles' and that what he needed was someone to speak to. Sam, however, was living alone and so he had no one at home that he felt he could talk to.

Sam spoke of the pandemic restrictions stifling the potential to be supported well by family and friends.

"If lockdown hadn't been a thing, I would at least have the option to go see friends or to travel through and see my mum etc., whereas I was very limited to just Facetime."

Sam's sense of isolation was compounded by the fact that his GP consultations were on the phone and not face-to-face. As his mental health continued to deteriorate, Sam had contacted his Community Psychiatric Nurse (CPN) who, in turn, had given him crisis numbers to call.

"So when I turned to professionals and the only option and help they could give me was verbal advice over a phone or 'call this crisis number', I was just like 'right ok, so I literally have no avenue to go down and that is because of lockdown'."

Sam found that his calls to the crisis lines only brought very short-term relief.

"So I would phone them when I got like bad, and they would just talk me down, and I just feel like it was a temporary fix, it was like putting a tourniquet on my mood, and then they would calm me down and then the problem would arise again."

"Obviously there's been a surge in mental health crisis during this lockdown, so I fully appreciate they probably are stretched very thin and their resources are limited, but I just felt like I don't matter, which just further fuelled my belief that I shouldn't be here and what's the point..."

A few weeks prior to this interview, Sam tried to end his life. Sam said that his suicide attempt galvanised services into action.

"It took like something drastic to get the ball moving, and that's what tied in with the feeling of being fobbed off. I'd been saying to them for months I'm really struggling and it was just the same answer back and forth."

Sam now has a different GP who he describes as 'incredible', 'like a godsend'.

"I got put to this new GP and then I just clicked with her straight away when I spoke to her. And then I just said that to her, 'I feel a lot more comfortable with you', and she was like 'well just ask for me from now on'. So she's now my GP."

This GP now calls him every week. Sam values the frequency and regularity of these calls and that she listens to him and is empathetic.

"She listens and she's willing to explore other avenues with me. She's attentive, she calls, like she's chatty. She talks to me like I'm a person rather than a patient, which is a massive thing."

Sam says that the support from the mental health resource centre has improved: they 'have upped their game', are now more attentive, calling Sam every week to see how he is getting on.

Sam has been referred for psychotherapy. This referral was four weeks prior to the interview, and he has not yet heard the outcome of this, and has no idea when he is likely to do so.

While Sam continues to experience low moods, these are not as intense as they were previously. He is now feeling more self-sufficient, using 'healthy coping mechanisms' (such as exercise) to help deal with his mood swings.

His greatest worry is that there is another lockdown and that services forget about him.

EXPERIENCES OF CARE

ACCESSING SUPPORT

Participants received care from a variety of sources: primary care; specialist mental health support such as a Community Mental Health Team (CMHT) and the third sector. Primary care, particularly GP services, are a key route to mental health support. In our third survey, nearly two thirds (64%) of respondents reported that they had tried to speak to a GP about their mental health since the pandemic began. Over one in ten (13%) had been unsuccessful.

Challenges in accessing GP support included the inability to have face to face appointments, the need to rely on call backs from GPs and perceived gatekeeping by GP surgery staff:

"I was unable to get in touch with my GP as easily before. I felt that I was chasing them constantly and the GP surgery/reception staff weren't taking my mental health seriously because it wasn't a physical condition. On one occasion, after waiting all day for the duty doctor to call me, I was told – 'this is not urgent'".

[Survey1respondent]

Over half⁷ of those who took part in the research had accessed support from specialist mental health teams such as Community Mental Health Teams (CMHTs). Over 80% of people who attempted to access specialist support during the pandemic managed to do so. However, it's likely that this related to accessing support that had begun prior to the pandemic, rather than successful referral to specialist services during the pandemic. In our third survey, over a quarter of respondents (27%) stated that their specialist treatment or care had stopped because of the pandemic.

Generally, those with continued support were relieved and grateful that it had continued. [What matters most is] still being able to work with my counsellor [via Zoom] has been a lifeline, I would have really struggled without that" [Survey1respondent]

"I'm happy that the services that I've been receiving [previously] I'm still receiving them [now], and that's where it becomes acceptable, at least it's not just been cut off".

[Luke, interviewee]

SATISFACTION WITH CARE

Across the research period, survey respondents were more likely to report satisfaction rather than dissatisfaction with the care they had received. Positive experiences were most likely to be mentioned in regards to individual relationships and continuity of care with practitioners and services.

"My psychologist has been, especially at the beginning, really good at phoning, like initially every couple of days and that, just to check up on me, and that's kind of kept going on like weekly and stuff like that, so that's been really good". [Dawn, interviewee]

Results from the second survey highlighted the following areas where respondents reported a more satisfied than dissatisfied experience:

Being able to have contact with the service:

Satisfied (46%) Dissatisfied (23%)

How long it takes for the service to respond when I contact them:

Satisfied (57%)

Dissatisfied (23%)

Being able to have contact with the individual(s) who had been treating or supporting me:

Satisfied (50%)

Dissatisfied (27%)

The amount of time I have contact with the individual who has been treating or supporting me:

Satisfied (49%)

Dissatisfied (30%)

The quality of my treatment/care:

Satisfied (45%)

Dissatisfied (25%)



[What matters most is] still being able to work with my counsellor [via Zoom] has been a lifeline, I would have really struggled without that"

[Survey1respondent]

It is clear that respondents highly valued the care and support from the people who provided their treatment, particularly where this was consistent and accessible.

Our third survey found mixed levels of satisfaction with different aspects of care and treatment. Roughly equal numbers reported being satisfied and dissatisfied with how supported they had been by their GP. Just over two fifths (41%) stated that they were satisfied with the quality of GP care and treatment, with a third (33%) expressed that they were dissatisfied. Respondents were more likely to be dissatisfied with crisis care from their GP, with a third satisfied compared to over 40% dissatisfied. Professional consistency - such as being treated by the same practitioner - was highly valued for both primary and specialist support.

"I think like it's been really good having like the same psychologist, so that's like continued, because I've been with her for a while, so I found that really helpful, just continuing with that, and it's just been really good having to then talk about how the pandemic's affecting me." [Dawn, interviewee]

The research highlighted clear dissatisfaction and distress arising from systemic problems and changes to the delivery of mental health care and treatment during the pandemic.

Our third survey asked people how care and treatment had changed over time. There was a general agreement that care and treatment had worsened as the pandemic continued. For example, a substantial minority (45%) felt that the quality of their treatment from primary care had got worse. A similar proportion, just under half (47%) of participants felt that the quality of their treatment from specialist services had worsened. Over half of respondents (54%) felt that their opportunities to discuss treatment in primary care and specialist care (54% and 52% respectively) had got worse.

Dissatisfaction and concern increased as the pandemic continued, with our third survey finding that around half the respondents felt there had been a worsening in their confidence that they would receive the mental health treatment or care that they needed.

EFFECT OF CHANGES TO CARE AND TREATMENT:

Common themes included increased feelings of isolation, abandonment, fear and confusion in how to access support.

"I have been removed from the list, so I have no CPN or psychiatrist. I have no one to contact other than emergency CATs team or Samaritans. I am concerned I need contact before I get to that point. I feel abandoned and terrified". [Survey 2 respondent]

In some cases, a lack of 'check ins' from services compounded the feelings of being abandoned and forgotten about:

"I need that check-in with somebody to say 'look ok, I hear you, I see you, you're doing well', if in fact I'm doing well, right? And that hasn't happened for almost a year now".

[Barbara, interviewee]

Indeed, our second survey found that over 70% of those who answered our question on isolation indicated that they had felt alone and/or isolated more than before the pandemic. "I need that check-in with somebody to say 'look ok, I hear you, I see you, you're doing well', if in fact I'm doing well, right? And that hasn't happened for almost a year now".

[Barbara, interviewee]

"My psychologist initially phoned and then contacted me through video call. I had to wait longer between appointments, at one point up to five weeks".

[Survey1respondent]

Feelings of abandonment and isolation were compounded not only by changes in care and treatment but also by the ongoing lockdown restrictions which limited social contact with friends and family:

"Please campaign for mental illness exemptions to the no-one in your house rule and for larger bubbles for those who live alone and who are mentally ill, as this is crucial to our survival and wellbeing and currently we are being discriminated against hugely with no-one advocating for us - please help us." [Survey 2 respondent]

"Why is it okay for me to spend 22.5 hours with 26 households over a week [I'm a teacher] yet I can't spend any face-toface time with someone who can support my mental health? I feel like I'm more likely to die from my mental health than COVID even though I'm aware of its potential severity".

[Jim, Interviewee]

Interviewees spoke frequently about the importance of consistently seeing the same GP or other practitioner and an appropriate length of consultation. This was frequently highlighted as lacking during the pandemic and lockdown.

"It's made it harder to cope with things because I've not got access to somebody [GP] to speak to that knows me, that knows what helps when I'm struggling, what things work and what things don't help. So it's like...I kind of speak to somebody different every time. It's like a lack of consistency and they all say different things, and it's like that doesn't help me".

[Lucy, interviewee]

"No GP or anyone checking if I'm even alive".

[Survey1respondent]

Interviewees also highlighted other problems including feeling uncomfortable disclosing their mental health problems to GP receptionists (or GPs with whom they had no past relationship) and frustrations over the difficulty in addressing mistakes and mixups with repeat prescriptions and medication.

Other issues included a reduction in frequency of support from services.

"My psychologist initially phoned and then contacted me through video call. I had to wait longer between appointments, at one point up to five weeks". [Survey 1 respondent]

"I mean I go to see my psychiatrist every three or four months, and since Christmas I got to speak to him over the phone last week [September], that was the first time. And I was on the phone for about 15-20 minutes before he called a halt to it because he had to phone someone else, you know... it wasn't up to the standard of care that I would expect, you know, that I've had for maybe the last 30 years".

[Sheila, interviewee]

Some participants spoke about the delay and lack of promised check-ins following treatment at hospital including following incidents of self-harm:

"I got a phone call about four days later [after hospital discharge] I think from the Community Mental Health Team, after... so it took them four days to get...to even just check in and make sure I was still here basically, because I might not have been here".

[Douglas, interviewee]

"I got one phone call the day after I was discharged from hospital saying 'I'm going to be phoning you once a week for the next three or four weeks now, is that ok?' and I said 'of course it is'. She says 'right I'm not going to chat to you today because you've just been discharged but I'll phone you next week', and we arranged the date and the day before it I got a phone call from one of her colleagues saying 'oh I'm sorry she's not going to be phoning you tomorrow, she's off ill', and I said and 'who is going to be phoning me'. 'Oh, there's nobody going to be phoning you', and I said 'well I've got a few things I want to discuss'. 'Oh well, can it wait until she comes back?' "I said 'well by the sound of things it's going to have to, isn't it?'" [Barbara, interviewee]

A final issue raised by participants was that support from multi-disciplinary teams had become disjointed or stopped entirely.

"So it used to be like if... I was struggling or something, I'd be able to talk to them or something, or if I was struggling with my eating they would regularly check with like my weight and that to check that I was keeping healthy and that I was still being safe, but it was like none of that was happening. It was like whenever COVID came about, all that kind of stopped".

[Erin, interviewee]

THIRD SECTOR SUPPORT

A limited number of participants in the research talked about mental health support they received from the third sector, such as counselling and peer support. In all cases they were extremely positive about their experiences.

Case Study: Joe

Joe is a man aged between 35 and 44. He experiences anxiety/panic disorder, depression and an eating disorder, and has 'dibbled and dabbled in mental health services for about 'six or seven years'.

Joe talked of having '*a major, major blip*' during the coronavirus pandemic.

"I was feeling pretty down, and I've felt that loads of times - where you go, 'ach, I wonder what it would be like just to say cheerio to the world?'... I went from 'I wonder what it would be like' to 'I'm about to do this'. I didn't even have the- 'what would you do? How would you do it bit?' and that frightened me. I've never done that before, and that's why I went I need to speak to somebody quickly."

Joe did an online Google search for help.

"Sometimes you feel embarrassed going to Google and admitting mental health problems but I had to cross that stage and look for help."

Joe found, and got in touch with, a third sector suicide prevention organisation. Since then he has been receiving telephone counselling from them 'approximately once a week'. "I was offered if we wanted to increase the frequency, and I didn't feel I needed to increase the frequency, yet I really appreciated the fact that it was given as an offer."

Joe values these sessions. He finds they are helping him, and appreciates the relaxed and person-centred nature of the sessions.

"We can have a conversation and it doesn't feel like you're in a counselling session. It's not chatting...it's a nice mix of...you feel as though you're chatting with a friend, even though they're a professional, and there's no judgement and I'm comfortable with speaking to them and what they say, and actually listened to, and I think that's a very big point."

Joe feels reassured by the knowing he has access to help. He reflected:

"The help is there should I require it in the future, and I now have the knowledge of knowing where to turn. You don't need the emergency service, you don't need a paramedic or anything, you just need that friendly ear."

CRISIS SUPPORT

"I'm worried if I'm in serious crisis I will die".

Beyond GP and specialist support, the research also sought to explore people's experience of crisis support during the pandemic. Crisis support could come from a number of sources, including GPs, specialist mental health practitioners or people working in the third sector.

49% felt that GPs' crisis felt that crisis response was worse responses from since the pandemic. specialist services

41% were worse since the pandemic.

"Refusal to deal with anything other than COVID led to suicide attempts. No GP would see me or refer me even when I said I was suicidal on the phone. My appointment lasted 4 minutes in total because theyjust kept saying there was nothing she could do other than tell me to phone Samaritans."

Participants talked about:

- A reliance on phone support, including from crisis support lines, as the only source of help;
- A lack of consistency in who was delivering crisis care
- Support being short and perfunctory.

"I felt like I was screaming at a wall and I was just going round and round and round, and as I said earlier it was just like 'phone the crisis line', I phoned the crisis line, they calm you down or talk you off the ledge so to speak, that's it, and it was just the same thing over and over, and I'm just like this is not working, this is not getting better. I just felt like 'you aren't listening to me'".

Case Study: Gus

Gus, aged between 45 and 54 years old, has had schizophrenia for 37 years. As a child, he suffered abuse. This, he says, underpins his 'trust issues' and his discomfort in talking to someone he doesn't know.

Before the pandemic, he had been receiving regular treatment and support from a multi-disciplinary Community Mental Health Team (CMHT). This treatment had focused on not only his mental health but extended to his physical wellbeing.

"Up to that point I had my phone call every week, and sometimes two or three depending on how I was. I would see occupational therapy, I had a support worker that would take me out, like go swimming, go to the gym, just to make sure I was doing this to make sure I was getting physical exercise...because obviously with my hallucinations I struggle when I go out."

Initially, the post-coronavirus protocol was that Gus would speak to different psychologists on a rotational basis. However, Gus's psychologist had recognised that he would experience difficulties with this, so initially continued to provide treatment and care via weekly Zoom calls. However, these were reduced and then ceased altogether. This, Gus said, was because of the mounting waiting list.

Gus was given the telephone number of a crisis line. Gus's GP was displeased that he had no designated CPN to support him and contacted the CMHT. This prompted a phone call from a CPN,Billy⁸, who was known to Gus. Billy reassured Gus that he could phone and ask for him. However, Billy would only be contactable if he was on crisis line duty at the time.

"Billy said 'you can phone me, Gus', he says 'you can ask for me' and I said 'that's great, I can phone you Billy, I know you, I speak to you', he says 'yeah but only when I'm on crisis', and I went 'well that means I cannae phone you, that's means I'd have to speak to a stranger every single time I want to phone'". Gus found his calls to the crisis line unhelpful.

"So I tried to phone, and every time I phoned and told them I was struggling, things are bad, my voices are bad, my hallucinations are back, the only thing they'd every turn round and say is 'right ok, we're really busy, we're inundated, go and take Diazepam', that's it. That's their advice: 'go and take Diazepam... take more of your Diazepam, that'll make you feel better', 'no, it doesn't make me feel better, I need to speak to somebody, I need to tell you what's going on in my head.""

Gus felt that simply having access to a crisis line was totally inadequate for his needs: the calls were short, he would get referred on to another helpline who, in turn, would not be equipped to support him.

"There is nobody. I can phone up...you can phone Crisis, ok I can phone Crisis, and you're lucky if they talk to you for 15 minutes on the phone, and they'll tell you to phone Breathing Space or phone Samaritans if you cannae get through, and you're thinking, 'well that's not the answer either', because if you phone...and I've had experience of this as well, if I phone Breathing Space and I tell them how I'm feeling, because of what I've got, they say 'we can't handle it' and usually transfer me through to the mental health nurse, and then it flags up straight away, and before I know it I've got the police at my door to see if I'm alright, you know... That doesn't make me feel any better; that just frightens the crap out of me."

As a consequence of the cessation of CMHT support, and the lack of support he derived from the crisis line, Gus felt abandoned by services.

"You just feel like a forgotten child, you know? You're just like a lost child in the corner that somebody's forgot about."

Failure to get the type and level of support that he needed fuelled Gus's desperation and suicidal feelings.

"Why is the help not there for people with this?... you feel like there's nothing there and you think what's the point. What is the point? Do you know what I mean? And it's like...it's because there's nothing there. There just is nobody there."

PRIORITISATION OF MENTAL HEALTH

In general, the people who took part in the research understood and had empathy with the need for services to change how they operate as a result of the pandemic. But there was near universal concern that mental health and mental health support was not being adequately prioritised during the pandemic.

"There is an almost complete focus on coronavirus with very little mention of the many other problems that people in Scotland are experiencing". [Survey 1 respondent]

"I feel like you don't want to waste their time, like all they care about was COVID. I kind of get that feeling I think. Everything is secondary to COVID, which I get to an extent. But when it's mental stuff, it cannae wait indefinitely". [Anita, interviewee]

Survey findings supported these sentiments, with high numbers of respondents believing that mental health was less of a priority for the NHS or Scottish Government during the pandemic than beforehand.

In our third survey:

54%

of respondents indicated that things were 'worse now than before the pandemic' in terms of 'feeling that mental health treatment/care is a priority for the NHS'.

35%

indicated that things were 'worse now than before the pandemic' in terms of 'the Scottish Government's commitment to mental health'. Interviewees also discussed perceptions of priority within mental health services. Generally, there was a belief that services, including GPs could only support people at extreme risk, such as people were experiencing suicidal crisis. This made it less likely that people would seek support when they were not in crisis.

"I think earlier in the pandemic I kind of felt like yeah, everything was kind of secondary. My therapy was almost stopped because of COVID, but I was like at a really kind of crucial part, so they were kind of able to continue. But again, it just kind of felt like unless it's super serious, unless it's a crisis then it's not important enough". [Anita, interviewee]

"There are people that probably need it more, so it's like I don't want to take that away from other people that probably need it more than I do". [Lucy, interviewee]

"It just kind of felt like unless it's super serious, unless it's a crisis then it's not important enough". [Anita, interviewee]

60%

of respondents to our second survey indicated that 'I have felt like I am a burden to the NHS' 'more so than before the pandemic'.

54%

of respondents agreed that 'I have felt that I do not want to bother the professionals because of the pressure they are facing with the coronavirus'. "I have never felt more of a burden and I believe this exacerbated my symptoms" [Survey 1 respondent]

"I know I should have, like, probably spoken to some of these people earlier than I have... you know, sometimes you feel like you're wasting people's time and then it's like, I'm kind of put off phoning for help. I suppose just now because lots of stuff has stopped. Sometimes you feel they can only cope with like, you know, limited numbers". [Lucy, interviewee]

Fear of burdening the NHS and other services contributed to confusion about where and how to access mental health support during the pandemic.

"Even if it's just something really stupid, like having a question or like, if I'm like feeling really stressed or really anxious, where should I be turning? Should I be turning to the GP's office, should I be calling 111? I genuinely don't know". [Susie, interviewee]

Interviewee: Anna

Anna is aged between 18 and 24 years old. For several years, she has been receiving treatment, including as an in-patient, for her eating disorder.

In the run up to the pandemic, she was 'doing great': she had been out of hospital for some months, had achieved a health body weight, and was at a point in her treatment where she was focussed on accepting this. Prior to the pandemic, she had been seeing her psychologist on a fortnightly basis.

She was now receiving treatment on a monthly basis via a one-hour video call.

"When the pandemic hit, because a lot of things were moved to online apart from high priority cases, they are still being seen, I was then put down to, like, well you seem to be managing ok so, like, more or less you're managing ok... So it dropped down to about 4 weekly, once a month...."

While Anna acknowledged that it was 'an appropriate time for me to probably reduce the frequency of my treatment', she questioned whether the treatment would have been reduced as quickly had there not been the pandemic.

Anna had been allocated a different psychologist just prior to the pandemic. Because her consultations were online rather than in person, Anna found it difficult to develop a trusting relationship with this new psychologist.

Anna felt that the challenges in developing a strong therapeutic relationship (as a consequence of her treatment being online) undermined the effectiveness of her treatment.

"I think that face to face contact is key and is important, and I think that's one of the biggest things that I've been frustrated at, and I think it's been one of the biggest challenges. I've became really disengaged in my treatment a lot more because of that, like just that lack of...it's like a lack of human touch...when you're trying to feel human again and trying to feel emotion and trying to do these things - and in your treatment you're not really getting that kind of support I suppose." Anna talked of her sessions with a psychologist previously being 'basically the only treatment that I receive now', despite feeling like the sessions should be 'just like one part of my treatment'. This contrasted with the multi-disciplinary treatment and care that she had previously received.

"Before the pandemic, I had been attending supported lunches, attending, like, therapist groups ...and getting physical monitoring, so that's, like, bloods by the eating disorder team and ECG and stuff, and then all of a sudden ...when the pandemic...it threw that out more or less - and I've never been offered [more] since."

Furthermore, Anna felt that the good communication that had previously existed between the eating disorder team and her GP practice had deteriorated, and that her treatment had become disjointed as a result.

"Previously they did work quite well together, but I had been caught up in waiting on lots of, like, examinations in hospital and it seemed that, like, during the pandemic the kind of link between the mental health service and the GP service kind of just fell away. It was really disjointed"

Anna was frustrated that her recovery was not progressing as well as she felt that it might have under more conducive circumstances. Nevertheless, she felt that the pandemic had reduced her reliance on the eating disorder service. This has contributed to her increased sense of resilience.

"I think the only good thing that has came is that - I probably think it's maybe made me a bit more resilient, whereas before I was really, really reliant on and I think in my own head...because I felt lost without the service, but I think with, like, the fact that it forced me into an uncomfortable bubble where I had to deal without having – like, at one point I think I attended the service almost every day in the week"

While Anna felt more resilient, she worries about the nature and level of support that she could expect in the future, and whether the pressures on the service may lead to her being discharged before she feels ready for this.

MENTAL HEALTH, COPING AND RECOVERY DURING THE PANDEMIC

We asked participants for their self-reflections on their mental health over the course pandemic.

MENTAL HEALTH

"I feel like giving up to be honest... I did decline with my mental health quite a bit. I think especially when they're talking to people on the phone, they really need to kind of take the time to kind of sit down and kind of hear the person out and listen to what they've got to say". [Erin, interviewee]

All three of our surveys found significant numbers of participants felt their mental health was poor or very poor.

In our final survey participants stated that their mental health was:

recently poor or very poor 53%

very poor 32%

good or very good 12%

As the criteria for inclusion in the research included having experienced recent care or treatment for mental health, this high level of poor mental health may not be surprising. But what was striking was the apparent deterioration of participants' mental health over the course of the research.

For example in the first survey, just over two fifths (42%) of respondents said that their mental health was worse since the pandemic. Over three fifths (62%) said their mental health was poor or very poor at the time of the survey, compared to two fifths (42%) describing their mental health was poor or very poor in the six months prior to the pandemic.

This deterioration in mental health continued as the pandemic went on. In our second survey, half of respondents said that their mental health had been 'a lot worse' or 'a bit worse' in recent weeks compared with earlier in the pandemic. Similarly in our final survey,

56% stated that their mental health has been 'a lot worse' or 'a bit worse' in recent weeks compared with earlier in the pandemic.

A number of interviewees did speak about increased resilience and self-help strategies to better manage their mental health during the pandemic:

"I'm still trying to work out what my options are. I'm going to look online again today and see if there's any kind of like online mindfulness courses and stuff that I can do...to do myself. But I do kind of feel that my mental health is in kind of my own hands at the moment. So yeah, it makes me less willing to want to kind of reconnect and reengage. I think I will do, because I think it's getting to the point that I kind of need to see where I'm going with this, I don't want to get any worse. But it's not something that I am like super psyched to do." [Susie, interviewee]

"I guess the only thing that's been good is that I've had to be a lot more selfsufficient and learn to execute like a level of control when I'm having low moods, so...just like go out running and stuff like that, like use healthy coping mechanisms" [Lewis, interviewee]

COPING

Participants were asked how they were coping during the pandemic. The third survey found that a large proportion felt that they were not coping well.

37% stated that they were coping 'quite badly' or 'very badly' in recent weeks (since November 2020)

This compared to one fifth who said they were coping 'quite well or 'very well'.

The surveys highlighted a deterioration in participant's ability to cope as the pandemic continued. For example, findings from our first survey showed that while just under a quarter (23%) indicated that they had been coping 'very badly' or 'quite badly' in the six months prior to the pandemic, just under half (45%) indicated this to be the case since the pandemic – approximately doubling since the pandemic began.

Our second survey in September 2020 found that nearly half of respondents (46%) felt that they were coping worse in recent weeks compared with earlier in the pandemic. In survey 3, among those respondents who had completed survey 1 and agreed to be followed up, a modest increase was found in the proportion of respondents saying they were not coping. Here just under 39% reported to be coping 'quite badly' or 'very badly' in recent weeks, whereas in survey 2, 36% reported this.

RECOVERY

"I wasn't immediate risk. I understand, like, it is obviously a service that need to deal with people who are kind of at life and death situations, and I wasn't at that, but I was so frustrated that the service almost took me right to the bottom of the pile and didn't see the opportunity of capturing...I feel that if they'd captured my treatment at the right time, then I could have been so much more progressed in my recovery, but I was kind of left to deal with it quite like alone, so that's how it was so frustrating". [Sophie, interviewee]

The ongoing pandemic and changes to care and treatment have affected people's mental health recovery journeys. Half of the respondents to our third survey stated that their resilience was 'worse since the pandemic' compared to how they felt before, with only a fifth feeling that there had been no change in their ability to deal with challenges themselves during the pandemic.

Similarly, just under half of respondents (46%) to the third survey stated that their levels ofprogress or recovery had worsened since the pandemic compared with before. Just under 28% felt this was unchanged, with 14% saying their progress/recovery was actually better since the pandemic than before it.

recovery worsened 46% unchanged 28% better 14% "It just kind of felt like unless it's super serious, unless it's a crisis then it's not important enough".

[Anita, interviewee]

About SAMH

SAMH (Scottish Association for Mental Health) is Scotland's mental health charity. We're here for your mental health and wellbeing providing local mental health support and always accessible information. We listen to what matters in each local community, and campaign nationally for the changes that make the big and little differences in life. Now more than ever, we need to make change happen.

We're standing up for Scotland's mental health.

If you need information about mental health

SAMH is committed to supporting Scotland's mental health, especially during this difficult time. We've created a dedicated online information hub, providing for advice and information on protecting your mental health during these developments. Visit www.samh.org.uk/coronavirus.

If you have a general question about mental health, we can help. The SAMH Information Service provides information and support on mental health. Whether you're seeking support, are looking for more information for you or someone you love, or just want to have chat about mental health, we're here.

Tel: 0344 800 0550

Email: info@samh.org.uk

Web: www.samh.org.uk/info

ENDNOTES

- 1 Scottish Government <u>Coronavirus (CORONAVIRUSCORONAVIRUS)</u>: mental health transition and recovery plan 2020
- 2 Scottish Government Mental Health Strategy 2017 to 2027 2017
- 3 Scottish Government <u>Coronavirus (CORONAVIRUSCORONAVIRUS) confirmed in Scot-</u> land 1 March 2020
- 4 Scottish Government Effective 'lockdown' to be introduced 23 March 2020
- 5 Scottish Government <u>Coronavirus (CORONAVIRUSCORONAVIRUS)</u> update: First Minister's speech 28 May 2020 28 May 2020
- 6 BBC Mainland Scotland moves into level 4 lockdown 26 December 2020
- 7 Over half (55%) of respondents in survey 1 had done so since January 2019 and in survey 2, well over half (65%) had recent contact with a CMHT.
- 8 Not his real name



for Scotland's mental health

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