



## 1. Overview

This briefing shares the insights that Rethink Mental Illness has gleaned on service support and digital solutions during the pandemic. Some of these insights are based on online research we have conducted with service users, which we have plans to continue, as well as information we have gleaned from our services.

Some of these are existing services, others have been launched in response to or adapted as a result of the crisis. We have also include proposals we believe could offset the impact of the pandemic, benefitting service users and carers and reducing inappropriate pressure on the system itself.

Unsurprisingly, there is no single overarching finding or one size fits all solution. Experiences and available support vary from person to person and place to place. How do deal with many of the problems that have arisen during the pandemic is inherently complex and challenging.

Despite these nuances, there is an arc that suggests that the more severely affected by mental illness a person is, the less likely there are to find that digital support meets their needs, though there will always be variations from person to person and service to service.

The following sets out some of the challenges people severely affected by mental illness have faced during the pandemic, poses questions and suggestions on how they could be addressed, and sets out how Rethink Mental Illness itself has adapted to this new environment.

## 2. Crisis research

Below we explore the qualitative responses given by service users who are in contact with crisis, Early Intervention in Psychosis (EIP) and liaison and diversion services, as well as those who have been inpatients within the last 12 months, in response to the following question:

*'Please describe how the support you receive has - or has not - been affected by coronavirus'.*

A total of 272 people in these categories responded to our online survey, which ran between April 17th and 10th May 2022. Some of these respondents selected more than one of these options. The themes that emerged are:

### **Positive experiences and recognition of the circumstances**

We received several examples of services going to great lengths to support service users during extremely challenging circumstances presented by the pandemic. There was also a recognition of the difficulties services face in continuing to support people during this time and that remote support was the best that could be expected. A very small number noted a benefit from changes in support they have received.



*'The Covid-19 Situation, and because I am lucky enough to live in a Shared Supported House has meant a certain, 'insulation effect' from this issue. Support from Medical and Mental Health Services has continued mainly as normal, albeit remotely / over the phone. This should be a model for the future'*

*'My GP has been superb and speaks to me weekly. She has also increased the dosage of my medication. All of my other treatments are now video calls, when I was seeing the people in person previously'*

*'I'm still lucky enough to be contacted as frequently as I'm usually seen which most probably aren't so I'm very grateful I just find phones much harder than in person due to anxiety and find in person appointment more beneficial'*

*'Initially everything was simply cancelled, however recently video appointments have been introduced which is the best option under the circumstances and feels sufficient, I have no issues there'*

### **Challenges in remote delivery**

Despite the examples above, the majority of the qualitative response demonstrated that service users are struggling with the delivery of remote services, or have seen a drop off in the level of support they have received. A concerning number have received no support at all.

Several respondents noted that the nature of the support they receive has changed, that they struggle to be as honest in their remote sessions, and that the length of their appointments has reduced or their support has become less regular. Others have struggled to access helplines or reported that navigating access to support has been more challenging in the current environment. There appears to be some possible confusion over the purpose and expected outcomes of remote interventions. It is crucial that services make clear to service users the remit of the remote intervention to manage expectations and help the transition from face to face to virtual support.

*'I get a weekly phone call that lasts about fifteen minutes, advice is the same every time with no acknowledgement that advice isn't helping, despite being high risk and a former inpatient'*

*'No one visits just phone calls I can't talk on phone my mom does it'*

*'I left inpatient care earlier than planned due to the effects of lockdown on the hospital. The level of support in the hospital was reduced. I can't access my planned follow up care as a daycare patient due to lockdown so am doing Skype therapy which is fine but not ideal'*

*'My support workers can't see me in person so they can only go by what I tell them. Not by what they see'*



*'Everything from the CMHT is by phone now and I miss face to face visits. Services feel distant even though I can phone at any time. There can't be any 4 way meetings (e.g. psychiatrist, CPN, me and my carer. My GP uses video conferencing which is very good, but MH services don't have this'.*

*'Just quick phone calls instead of face to face appointments'.*

*'No face to face contact despite having been intubated and ventilated for 5 days in March before being able to breathe again due to an overdose. I live alone and have no support network and just phone contact has not been enough'.*

*'Only one phone call per week. No therapy'.*

*'Change to routine - staff not in services as regular or as readily available'.*

*'No face to face. There's a reason for face to face with mental health. I can't be honest and feel so cut off. I am in crisis a lot of the time and I don't want to explain this to services. Maybe when it's face to face they can read much more into it just by reading your body language etc'.*

*'Community mental health team contact me by phone or video calling so are keeping an eye on me and psychologist is continuing with my formulation. However I say that I am okay even if I am not as I am afraid of the corona virus'.*

*'Phone anxiety is making it harder to be honest during online therapy sessions'.*

*'I get a phone call now. Just not the same and it's very brief'.*

*'I can't go to the clinic. The crisis number is always engaged'.*

*'The effect of the pandemic has been to add an extra layer of indecisiveness and delay. Most communication has been by phone, home treatment does not appear to be an option (I've been told the team is working in more limited ways and under great pressure) and the threshold for admission seems to be even higher than it would normally be'.*

## **Recommendations on change to delivery of services/digital solutions**

- Policy solutions for digitally excluded people are urgently required and should be a priority for NHS England and the government. Urgent research is needed into the extent of digital exclusion among people severely affected by mental illness and their experiences of remote mental health service delivery and during the current crisis.
- As lockdown restrictions are lifted, digital and telephone consultations should continue to be provided, but as an *enhancement* of options for service users who prefer this method. Face to face consultations must be re-introduced as soon as possible for the significant proportion who respond best to support in person.



- Service users must be involved in designing and delivering mental health services during and post-pandemic, both at a national and local level – only then will we ensure services are supporting people severely affected by mental illness effectively, particularly in the face of a future mental health epidemic.

## **No support and cancellations**

Whilst the difficulties in accessing and benefitting from remote support as it is currently being offered are concerning, more so are the number of people who told us that they are currently receiving no support at all.

These responses can be broadly categorised into two parts: those who have received no support (either that they were told to expect or having receiving no contact at all), and who have had their support cancelled. People who have a Community Psychiatric Nurse (CPN), or whose responses suggest they may have a CPN even if they did not specifically state this, appear to have received no communication – even despite in some instances people proactively getting in touch with their care team.

We'd welcome more information on what guidance has been issued to Community Mental Health Teams (CMHTs) on how to communicate with service users during the pandemic. A pattern of people feeling like a burden, or being scared to make appointments because of the virus, also emerged.

This has had serious consequences for a number of people who are high risk, such as recent inpatients not being supported and incidences of self harm and suicide attempts leading in some cases to repeat admissions.

*'Since been discharged over 2 weeks ago I've had 2 phone calls and 1 visit from CPN, no GP follow up, and rushed back into hospital after an overdose'*

*'Seeking help in crisis has become much more difficult than it already was, the crisis team told me that I needed more support than the phone call we were having but in the end didn't actually provide me with any.'*

*'Since covid my weekly appointments have been cancelled so I haven't been seen for 2 months'.*

*'All appointments at my CMHT have been cancelled until the end of May'.*

*'My weekly therapy appointments (DBT) have been cancelled indefinitely. The out-of-hours Re-treats and Community Front Rooms have also closed down. Access to CMHT via telephone is limited'.*



*'Since transitioning to adult mental health services in February, I have not seen a psychiatrist from my team. With coronavirus, I do not know when I will see one'.*

*After spending more than a week in the ICU following a serious serious attempt I was discharged and have had no follow up except one crisis team visit the day after discharge. Services have not contacted me again and I haven't contacted them due to phone anxiety and not wanting to bother them. If it were not for coronavirus I would have gone home to see my GP in person by now'.*

*'I was having treatment for my PTSD and it's not happening. I had suicide attempts in the past which has lead me to almost being sectioned under the mental health act. I also had relapses and with treatment I can learn to manage my conditions and keep stable as without it I struggle and I don't want another relapse'.*

*'There is none. I have been ghosted. The system has forgotten me yet again'.*

*'I was intubated and ventilated for 5 days in ICU following an overdose in March. I haven't seen anyone from the acute mental health team since being discharged home'.*

*'Since coronavirus I haven't even heard from my therapist even though she was meant to come see me before lockdown, not as much as a text or call, I self harm and this has increased now to the point I do not want to be here'.*

*'Ashamed of how badly I'm coping and am not somebody who can reach out easily, if at all. My Gp monitoring me in my discharge plan but this isn't happening so nobody knows what effect my eating disorder is having'.*

*'My partner was discharged from a specialist eating disorder hospital in January with the expectation of a number of follow-up therapy/care referrals alongside constant monitoring of her weight and general health at her GP surgery, however none of this is happening because of the crisis'.*

People on a Care Programme Approach (CPA) should be followed up with seven days after discharge from a mental health unit, or after 48 hours if a risk of suicide is identified. It is vital that this continues to happen during the pandemic and we would welcome clarification on whether this is still expected.

## **Accessing medication**

Though we didn't prompt for answers on medication in the survey, the qualitative responses we received demonstrate that respondents are having numerous issues accessing the medication they need.



These include difficulties with ongoing access to depot injections, medicine shortages and difficulties accessing prescriptions both from clinicians and pharmacists. Some people have managed their own dosage or switched medications as a result.

We would welcome further clarification on what guidance is being issued currently about administering medication in homes versus hospitals. We understand there may be some challenges around entering service user homes because of compliance with distancing, but equally there are difficulties for service users going to healthcare sites because of shielding or anxiety about leaving the house during Coronavirus. Where shortages or changes in medication happen, the expertise of mental health pharmacists must be called upon to minimise side-effects.

*'I have had to fight to have my depot injection to be given to me in my home. I am so high risk. They want to stop giving me home treatment in 12 weeks but I'm worried to leave home in case I get CV19'.*

*'Fortnightly care coordinator visit & weekly OT activity both dropped, replaced with one phone call & one text message in six weeks - those face to face meetings were also PRN medication top up opportunities but I've kinda managed my use of those down to nothing through the lockdown'.*

*'Due to a national shortage of Depakote; it's taking longer for the pharmacy to order their stock. I order all of my prescriptions online with my GP Surgery and the GP's Pharmacist signs my prescriptions off'.*

*'No face to face visits, harder to sort prescriptions, zoom therapy sessions, harder to get hold of care coordinator, less access to crisis team'.*

*'The only difference from the CMHT is that my support has been via a telephone call rather than the usual home visit. I am very concerned about my regular Pych medication though, which I have been taking for 10 years - as this has been unobtainable for the past 4 weeks (Moclobemide), so I am currently having to manage on Quetiapine'.*

*'Getting support from mental health services has always been a struggle but these services are almost non-existent now. There has been a terrible lack of communication between my GP and the community mental health team. I have been told one thing and they another, there have been multiple drug errors. So much so my mother has started a complaints procedure with PALS'.*

*'I am more anxious but my GP won't prescribe any more diazepam'.*

*'I have struggled to get my prescription medication as there have been miscommunication between my GP and pharmacy, I am on a waiting list to see a CPN with no indication of when that will be, I have been on a waiting list for CAT therapy with the CMHT for 6 months with no indication as to where I am on the waiting list'.*



*'It's harder to get the right medication and I feel like I am a burden'.*

### **3. Further research on the crisis pathway**

Following on from the work above, Rethink Mental Illness will be conducting focus groups on people's experiences of the crisis pathway with NHSX, with the findings above serving as a starting point.

Participants will have a good understanding of the crisis services in their area, how they are and are not meeting people's needs, what has been different during the rapid response to the coronavirus, and how this difference has been helpful and unhelpful.

We will be happy to provide further insights on this work as it develops.

### **4. Insights from the Somerset Mental Health Alliance**

The Somerset Mental Health Alliance is a VCSE consortium of ten charities with Rethink Mental Illness as the lead accountable body, working in partnership with Somerset NHS Foundation Trust, Somerset County Council, Somerset CCG, along with voice of lived experience through our Experts by Experience Leaders.

In line with the Long Term Plan and the Community Mental Health Framework, we are redesigning community mental health services in Somerset. Our shared principles include that there should be no wrong door for service users to present at (indeed no doors at all), and that warm introductions for people should be made into, across and between different services, and joined up working and training for all delivery partners.

Trust between the different partners has been built up, enabling us to move quickly, and the knowledge and expertise of local charities has been enhanced where relationships with the community already exists. During the pandemic we have enhanced the existing Mindline helpline with new services. This means anyone in Somerset can be linked to an enhanced level of support on debt, housing, money advice, access to peer support, 1:1 remote access support, eating disorder specific support etc.

The helpline has been extended to all ages, 24/7, with on call clinical support, and a warm transfer through to other services. The response to the virus has galvanised the alliance, focusing our minds on what we know we can do quickly and what experts by experience tell us works for them.





VCSE and NHS staff have worked together as virtual locality teams so that partnership continues to develop during the pandemic.

The Alliance is also pressing ahead with work that can be started now and can continue post-crisis, such as one shared digital personal plan (including with the service user and carer permission), and ensuring that working groups continue virtually to maintain momentum in redesigning services.

We would be happy to share further details on the work of the Alliance on request.

### **5. Clic: no one should experience poor mental health alone**

There is already evidence that the UK's mental health is deteriorating at a population level. With funding from Public Health England, Mental Health UK, of which Rethink Mental Illness is a part, has established the Clic offer to help address some of these issues.

During a period when we when are forced to be distant from one another, including those we love, and many have seen their appointments cancelled. Our new online offer helps reduce the loneliness and isolation people with poor mental health experience. Clic is a facilitated peer to peer online chat and support forum. 1500 people have registered since early April and 14,000 posts have been made. The feedback we have received from users has is that people feel less isolated, have experienced improvements in mental health, and are more confident in discussing their illness.

We have an ambitious plan to grow the forum exponentially over the course of the year. Further details on Clic are available on request.

### **6. Our helplines: existing and new**

Rethink Mental Illness runs a large number of helplines aimed at different audiences, at both a national and local level including Gloucestershire, the Black Country, and South Yorkshire. We offer support to people at risk of self harm and suicide, carers, and those in specific demographic groups such as BAME populations. Our local level services provide emotional support and national services offer advice and information a range of issues including on housing, welfare and the Mental Health Act.





The overall picture highlights the challenges that the people we support are facing at this time. The number of calls and web chats and the length of time they take place for has increased from known users of mental health services. We have received double the amount of new callers from this time last year. This provides further evidence on the number of people experiencing mental illness for the first time as a result of lockdown.

We have received less contact from BAME callers, especially from our Asian helpline in Kent. We have undertaken informal research with those who we have been able to support. This suggests that people living with their families are not seeking support because of fears of being stigmatised due to their mental ill health. Lockdown has meant that where previously people could contact us whilst at work or in their free time, cannot access remote or telephone support because of their continual proximity to family.

Our data shows increasing mental health support lines during the pandemic, which is likely to continue throughout its course, and in our online research many people said they were unable to access telephone-based crisis support.. This points to a large unmet need among people for whom

support that may not be readily available. In recognition of this need, and that A and E is not the best place for someone in mental distress, Rethink Mental Illness has developed a national 24/7 mental health helpline proposal.

Building on our experience of delivering other services of this type both locally and nationally, we will work with commissioners to understand need and design staffing to respond appropriately to the number and nature of the calls we receive. Our service would be built on the principles of active listening, caller-led conversation, motivational interviewing and solution focused approaches, with the aim of escalating crisis.

Our staff would be trained to immediately assess risk and escalate calls to emergency service, police, and crisis / home treatment teams if required. We will shape our service according to the people who have come into contact with the service, establishing a Project Steering Group of service users and community stakeholders to ensure the continuously development of our offer. We would be happy to share further details on our proposal on request.

### **Further information**

For further information on this briefing, please contact Jonathan Moore, Head of Social Policy, at [jonathan.moore@rethink.org](mailto:jonathan.moore@rethink.org) in the first instance.