



Adult Secure Service User, Family and Carer Feedback Survey during the Coronavirus (COVID-19) pandemic

March-June 2020

Contents

Foreword	4
Introduction	5
Background	6
Themes	7
Activities	8
Outdoor access	11
Leave and progress	13
Communication	16
Digital access	18
Contact with family and friends	21
Preventing the spread of COVID-19 in secure services	23
Physical health	27
Staff	31
Other themes	33
Acknowledgments and thanks	35
APPENDIX ONE – Example Information Sheet & Survey	36
APPENDIX TWO – Methodology	39
APPENDIX THREE – Overview Of Statistics	41

Foreword

The NHS England and NHS Improvement Adult Secure Clinical Reference Group (CRG) were very keen from the outset to hear from and understand the experience of people in adult secure and forensic community services, their families and carers during the early part of the COVID-19 pandemic.

This information is crucial to recovery planning and when considering what a potential second wave and local lockdown arrangements might mean for the adult secure pathway. The CRG want to ensure that the information in this report supports national, regional and local discussions across adult secure services to ensure future planning considers the findings from the survey. We realise that the impact of the pandemic continues and appreciate this is an ongoing process to ensure that the views of experts by experience continue to be heard and shared.

Introduction

Rethink Mental Illness believes that a better life is possible for everyone severely affected by mental illness. The Coronavirus (COVID-19) pandemic has impacted everyone in the country, including people in secure services, their families and carers. Working with NHS England/Improvement (NHSE/I) who commission adult secure services, we have explored this further, finding out from people directly through a survey, what has been the impact of COVID-19 for them.

What we did and why

In collaboration with NHSE/I and in consultation with a group of Experts by Experience who work regularly with NHSE/I Adult Secure Specialised Commissioning and Secure Care Programme teams, we developed a survey to gather the views and experiences of people in adult secure services, in adult secure services in all service categories including mental illness, Personality Disorder, Learning Disability and Autism (both in the hospital and the community), and their families and carers, to find out the impact of COVID-19 on them from March to June 2020.

We found out what is working well for service users, families and carers, what is not working so well and what improvements people would like to see during this time. We heard about the things that had happened as a consequence of COVID-19 that people would like to see continued in the future. We also asked people what else they'd like to tell us about their experiences during this time. We received responses to the survey from 368 people from high, medium and low and community forensic services.

This report provides an overview of the responses we received which we hope will support regional and local discussions across adult secure services, especially as part of their recovery planning and also in relation to the impact of

any local lockdowns or a second wave of the pandemic. We wanted to ensure that the voice of people in secure services and their families and carers can influence how services are commissioned and delivered.

How we did this

Responses to the survey in the main were almost all handwritten, scanned and returned to the Recovery and Outcomes team to collate and analyse, pulling out multiple themes per question while ensuring that individual issues and information were highlighted and recorded. As emerging themes within the survey were nuanced, we were led by the voices of lived experience which have shaped the report. We have highlighted areas of practice that were described as helpful and reflected on other areas that we felt might be strengthened.

What we found

The most striking finding was the considerable variation in responses – both between services and within the same service. This report sets out 9 key areas where people identified examples of what is working well, as well as where lessons could be learnt and improvements made, not only for a potential second wave of the pandemic but also to ensure long lasting improvements for services as a consequence of this experience.

Background

Rethink Mental Illness is a charity that believes a better life is possible for everyone severely affected by mental illness. In addition to providing services for people living with mental illness, such as housing, employment, advocacy, training and education, Rethink Mental Illness has delivered the Recovery and Outcomes Network for people who use adult low and medium secure mental health services in England, over the past 5 years.

Through the network of involvement groups, we have enabled people to influence local and national policy, while also supporting people who attended as part of their own recovery journeys. We are delighted to have had the opportunity to organise and facilitate the Adult Secure Service User, Family and Carer COVID-19 survey.

We are living in very unusual times. The COVID-19 pandemic has impacted on the lives of everyone in the country, including the people who are currently placed in adult secure services and their families, friends and carers. Through this survey we have been able to systematically find out more – much more and have been bowled over by the response. We are humbled by the amount of time people have taken to complete the survey, with many running out of writing space on the survey forms, such as the desire of people to share their experiences with us. We are enormously grateful to all the staff in services that have helped facilitate the survey – by supporting people to complete the surveys, to scanning and emailing up to 40 responses per service. We are indebted too to the families and carers who also took time to respond – often with very personal accounts of what life has been like for them at this time.

Through the survey we have heard about people's experiences on a complete spectrum – from really challenging situations, through to stories of enormous resilience in the face of sometimes extreme adversity. People have shared with us their fears, their anxieties, and their hopes for the future. An enormous number of people have shared with us their heartfelt gratitude to other people – both staff and peers – for their support during this difficult time. We have learned such a lot about how services have coped – and sometimes been really challenged – and how helpful suggestions have emerged to support service improvement.

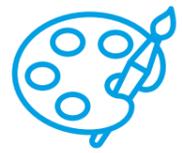
One of the strongest messages to come out of the survey has been about the variation in people's experiences both between different services and within individual services themselves. The caveat of course, is that there is also great variation in how people themselves have coped during this time and the responses are of course all subjective. As with any aspect of our daily lives, some people have found it easier to manage the situation while others in a similar situation receiving the same service have not found it quite so easy. We believe that this is another example of the importance of person-centred and collaborative care and support for people's recovery – even, and especially, during times like these.

Themes

The following sections of the report are an analysis of the most common themes:

- **Activities**
- **Outdoor Access**
- **Leave and progress**
- **Communication**
- **Digital access**
- **Family and friends contact**
- **Infection control**
- **Physical health**
- **Staff**

We have included areas for further consideration at the end of each section, which are based on the analysis of the themes which we hope will contribute usefully to the main purpose of the report. This will ensure that the voice of lived experience will help shape the recovery of services and contribute to the continued improvement of secure services.



Activities

- It was clear that for some people, having activities to keep them occupied during this time was working well.
- However, many people told us that their regular activities had been cancelled and this had been difficult – particularly group activities both on the ward and with people from other wards.
- People also told us that they would like some of the new activities that had been organised for them continued after this period.

‘Having activities during the day. Group discussion, chatting openly and honestly with staff, having Quality time with staff. Staff getting involved in activities e.g. Pop Art, creating artwork, Competitions.’

A person in hospital, Q1

Both between services and within the same service there was a marked variation in responses about ‘activities’ – enjoyable ways to spend time, relieve boredom and improve wellbeing. People told us about access to activities, the range of activities available, whether they were individual or in groups and whether they were available on or off the ward.

As a theme, activities were mentioned:

- **Question 1¹:** 79 times out of 344 responses – 2nd most common theme
- **Question 2:** 49 times out of 333 responses – 4th most common theme
- **Question 3:** 59 times out of 322 responses – 2nd most common theme
- **Question 4:** 56 times out of 282 – 2nd most common theme
- **Question 5:** 13 times out of 274 – 6th most common theme

In question 1, the increase in range and availability of activities was often mentioned, with one respondent saying, **‘we are doing more activities + OT’s creating projects for us to work on, during COVID-19’**. Another said, **‘Groups being put on the ward and games sessions helping to pass the time’**. The impact of having more activities on the ward was also mentioned, for example, **‘I have improved my social life, engaging in various activities’** and **‘The activities e.g. movie club, bingo even if you don’t do them it is good for the ward it brings a good atmosphere instead of people moaning’**.

It was clear that some wards had introduced new activities to the ward, such as **‘gym on the ward’** and people said that they would like to see these continued. Another person associated increased activities such as these with improvements to their physical health, such as **‘Manage to go to gym more and control diet’** and wanted **‘Gym sessions to continue’**.

Among people who said that they would like to see the increased activities on the ward continued, one person said **‘To keep up the activities which give purpose that day. As some people don’t have leave. Continue the ward group activities that did not happen so much before.’** One respondent described a mixed picture, saying **‘We have all been given more recreational thing to do with has been a big help’** but also **‘Our activities have suffered a bit due to restrictions where patients have not allowed to have mingled with other wards’** and **‘We would like a wider and more range of activities’**.

Some people commented that life on the ward was **‘boring’** and that there were insufficient activities to keep them occupied. Of the 31 respondents who said that **‘nothing’** was working well, some later commented in responses to other questions that this was because activities that would otherwise keep them occupied had been cancelled. It was not always clear whether people were referring to on-ward or off-ward activities. Others said they were keeping themselves occupied in their rooms and that was helping them cope with life during COVID-19 with **‘reading, magazines, writing letters, watching TV.’**

The survey did not distinguish between different wards within the same service, but from the variability between responses from the same service, it was clear that there were differences between wards in the activities that were available. This variability was partly down to which staff were facilitating the activities, for example, **‘Our OT is really good at finding ways to make as much as possible accessible. Whether getting hold of craft supplies, adapting recipes. This helps show us how creative thinking can overcome a lot’**.

There were several responses where people gave the names of specific members of staff who had been particularly helpful, for example **‘S and R were and are helpful with patients...fun and passing time with lots of activities and setting up a cinema room for us’** and **‘the exercising we do with S and R as a gym session’**. It was not clear whether these were ward staff or people who worked across several wards.

One response commented on the impact of having people from outside the service facilitating increased activities, saying **‘Volunteer office are sending the patients goodie bags with paper/puzzle activities, and information about the coronavirus with recipes for fun food to keep us busy. That was a kind thing.’**

Many people said that they missed having group activities and that this was something they would like to see reinstated as soon as possible. For example, people missed having access to vocational and educational activities that would usually be facilitated in groups, such as woodwork, gardening and working in the hospital shop. One respondent however said that they had been able to continue working in the shop and commented how important this had been to them. This was in part due to the impact of the relational aspect of **‘doing activities together’**.

The quote at the start of this section is an example of how some people commented that increased joint activities with staff had had a positive impact on their relationships.

¹ For details on the questions asked in the survey please turn to the Methodology in Appendix Two on page 39.

Some people said that not having leave prevented them from accessing activities such as **'shopping'** or activities beyond the service that they valued and provided a sense of **'normality'**. We did not ask people to tell us the level of security they were in, so it's not possible to distinguish where respondents are in their recovery journey and what types of activity they would be engaged in usually. Such information may have provided a better understanding of the impact of changes in the provision of activities.

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Working together with staff to co-produce:
 - activities that are available to people to replace those that may have been lost as a result of COVID-19.
 - a timetable of activities at ward and service level that meets the needs of everyone.
- Having a 'peer-based approach' to positively encourage joint activities.
- The right skill mix of staff to facilitate and reflect the co-produced activity timetables including, for example, Occupational Therapists, Qualified Exercise Professionals, Education staff, Activity Coordinators and other ward-based staff.



Outdoor Access

- People clearly valued having outdoor access during this time, but there was considerable variation in both access and the processes for gaining outdoor access.
- Some people didn't have outdoor access every day, whereas for others they had more than usual.

As a theme, outdoor access was mentioned:

- **Question 1:** 24 times out of 344 responses – 9th most common theme
- **Question 2:** 16 times out of 333 responses – 8th most common theme
- **Question 3:** 17 times out of 322 responses – 10th most common theme
- **Question 4:** 9 times out of 282 – 10th most common theme
- **Question 5:** not mentioned

It was not always clear what specific type of access people were referring to for example ward or courtyard access or within or outside of the secure perimeter.

The respondents that reported that **'outdoor access'** was working well told us it was more frequent than usual and for longer periods of time. Some people said that this was because staff were more aware of the importance of this, given that restrictions were in place. **'Having garden access at any time and being able to have fresh air'** was working well for one respondent who also said this should be continued in the future. Another person said they had been **'Walking round the football pitch and listening to music.'** Another said **'Letting us out in the garden, more garden leave even until late evening.'** Some people clearly related having outdoor access to being beneficial to their sense of wellbeing, with one person saying, **'When we had no grounds leave [my mental health] was bad'**.

Some of the people who had less outdoor access than usual said that they were not getting as much fresh air as they would have liked, with one person saying **'we only get fresh air three times a week'** and another saying **'I only enjoy the garden and that's just once a week'**. One person said that **'For a few weeks we had no leave for exercise and now it is very limited'**, and the suggested improvement was **'More leave for groups exercise'**.

Others commented on the variability between wards saying, **'every other ward gets leave to the sports field, but we can't go out to the sports field at all!!'**. As an improvement, someone from the same service called for **'sports field every day for exercise'**. For those shielding, outdoor access was a particular issue: **'Being shielded on ward, only fresh air 10 min in garden area, whereas other non-shielded are allowed out in front.'** And another person shielding said **'I would like to get to garden'**.

Some people told us that social distancing and self-isolation were factors, saying that their outdoor space was not big enough to have more than a few people outside at a time and that this was difficult for staff to facilitate for everyone. Some people said that they would have liked grounds' access with other people, socially distanced, and access to their phone while outside: **'More mixing out in courtyard via social distancing.'**

At one service **'Each ward has been treated like a household. [We have been] using the gardens to play games and being outdoors.'** People from the same service said they would like to see **'more garden access'** continued in the future. Interestingly people from the same service reported a variation in policy and practice between different wards, with different levels of access.

As mentioned in the section on physical health below, some people said that reduced outdoor access had impacted on their ability to exercise as much as they would have liked, also linking it to reduced off-ward gym access and access to community leave. One family/carer of someone in hospital commented that **'Lockdown of the hospital has resulted in patients having very little exercise time outside. Every week there is days when there is no exercise time at all and on some days there is only one half hour. This is a big backward step for a patient who has been having unescorted leave in the community.'** This person also suggested that there could be improvements to how existing outdoor spaces could be used, saying that the service could **'Better utilise the enclosed external open spaces in the hospital more, for the benefit of all patients.'**

Some people said they understood the reasons for less access, the need to socially distance, reducing the number of people who could be outside at any one time and that they understood that this was also due to necessary changes in staffing levels. The importance of having fresh air was emphasised by a family member, saying that this had been an important aspect of their relative coping during this time. One person in hospital summarised what many others said – **'feel cooped up – feel frustrated'**.

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Having access to fresh air every day.
- Working with staff to co-produce:
 - policies about access to outdoor spaces and how they are used.
 - A programme of activities that could take place safely outdoors.

→ Leave and progress

- This was the most common theme in all of the responses to the survey and overwhelmingly people found the restrictions difficult.
- People cited a range of reasons for this – not being able to continue with community activities, feeling 'cooped up' and the impact on seeing friends and family.
- Some people linked these restrictions to the effect this was having on their progress and were frustrated that this was holding them up.
- There was also frustration for people that lockdown easing in the community was not always reflected in the lifting of restrictions in their hospital.

'Really hard without leave, especially for our mind, body, soul'

A person in hospital, Q2

As a theme, leave was mentioned:

- **Question 1:** 16 times out of 344 responses – 11th most common theme
- **Question 2:** 120 times out of 333 responses – most common theme
- **Question 3:** 93 times out of 322 responses – most common theme
- **Question 4:** 18 times out of 282 – 7th most common them
- **Question 5:** 7 times out of 274 – 12th most common theme

It was not always clear what type of leave people were referring to so here we have only included responses about grounds or Section 17 community leave. Some people referred to restrictions on leave as something that was not working well, and said **'Not able to go off the ward as much'**, or **'For a few weeks we had no leave for exercise and now it is very limited'**, making it difficult at times to know exactly what people were referring to. What is clear however, is that restrictions to leave have had a very big impact on people.

From all of these responses, there was marked variability in the management of leave between services and even within a particular service, with one person saying **'I feel it is not fair only one ward has leave, I feel it should be given to all wards'**. We did not ask about the level of security or ward that people were responding from, which may account for the differences. One respondent said, **'There has also been confusion with regard to my normal leave with me being told different things by different people. For instance, I was told that I could see my family in the park per the government's advice yet the hospital are now saying that this shouldn't be allowed. They are playing with peoples' lives and it is not fair.'**

Some people commented on the impact to their mental health that restrictions to leave were having. One person said, **'Not being able to go out on section 17 / this makes me feel depressed'**. Another person said that they were experiencing **'cabin fever'**. Other people said they understood the reasons for the restrictions and knew that they would be lifted in the future, though there was some anxiety around when this might be.

For some, restrictions to community leave were framed in descriptions of the limitations this imposed – opportunities for exercise and community activities, connectivity to the outside world, a sense of **‘normality’**, restrictions to activities such as shopping or **‘vising the local café’** or access to smoking. Many people cited the impact restrictions to leave were having on contact with family and friends, discussed below.

During the timeframe of the survey, the government eased some of the wider lockdown restrictions, and it was clear from some of the later responses that people were aware of this and felt frustrated that similar easing of restrictions was not taking place in their hospital, saying **‘The community has been given more freedoms’**. For others, the lifting of restrictions was being reflected in their access to leave, with one person saying, **‘I have also been allowed to go for walks as lockdown restrictions have lessened.’** Another person told us how restrictions to leave were being lifted, saying, **‘Now we have one hour ground leave, plus 2 hours community leave for unescorted patients per day. We can only venture out into the community within a one mile radius. We are not allowed into shops. I can now have visits with my family – but only in the grounds unsupervised.’**

One person also commented on the importance of being kept informed about the progress of lockdown easing, saying **‘Please will the hospital trust keep us fully up to date and informed of when any restrictions might be lifted, and when things like visits and trips to the community are to be reinstated. Thank you’**.

Impact on progress

Some service users and their families and carers commented on the impact of COVID-19 on people’s progress, continuing on their recovery journey through and out of secure care. It was clear from the responses about progress that there was a marked variability in the impact it was having on people, both at an individual level as well as between services. Only one person said in answer to question one that their progress was still going well, saying that they had **‘Progressed with U/E leave. Referred to LSU.’** Someone from the same hospital said that they were **‘Being stuck in the hospital and not being able to progress with my leave.’** Another person said, **‘Even though we are in all this my discharge planning has continued and a placement found – I had a virtual 117 meeting’**.

Most people who commented on their progress said that they just wanted **‘more progress’** with one saying **‘[I] want to continue progression to discharge.’** Similarly, another said that the pandemic was **‘Delaying Section 17 leave progress’**. Someone else told us that **‘Placements have been paused until further notice.’**

Another person said that **‘I am frustrated that my discharge keeps being delayed. I have completed therapies, + meds. My care package would not be too big as I have my own home to go to. I have applied for Tribunal, but I was hoping that I could be discharged to my family home who I have not spent time with in 8 years’**. It is important to note, some people said that the prospect of moving on was causing anxiety at the present time, with one person saying, **‘I’m a bit anxious about moving on...am anxious about moving to another place.’**

Some people said that they understood the difficulties, one carer said: **‘I was upset that my son hadn’t progressed as expected but now kept really well informed and understand the reasons why.’** Another carer explained how a planned discharge was interrupted:

‘My daughter has been waiting to move, and this has been impacted as follows:

- **Delay due to hospitals being uncertain as they went into lockdown about their plans (so it has taken ages for her to be assessed)**
- **The assessment has been done on paper – nobody has come to meet her**
- **She has now been offered a bed but the move cannot take place as the ward she is moving to is unsettled presumably in part due to COVID-19’.**

Another carer similarly said:

‘It is also a great shame that she has had to stop her first steps to getting out of there (voluntary work, unescorted trips out etc) – all put back! Nobody’s fault of course!’

For others, the current situation was clearly holding them up:

‘There have been issues with being allowed to go to my placement in the community despite the restrictions around lockdown starting to be lifted. I struggle to understand how people can now shop as much as they like yet I am not allowed to spend a day in my own self-contained flat. This is extremely disappointing although I would like to say that my MDT have been pushing for me to be allowed to go. The problems originate from senior managers.’

This person went on to say that as an improvement:

‘I would like senior management to be more flexible with regard to going to my placement. They should consider each case on its merit and not use blanket restrictions’.

Some respondents told us that the pause in their progress was having a detrimental effect on their

mental health. In the absence of other markers of progress this was now holding them back, with one carer saying:

‘My son came on leaps & bounds in X hospital – it was time for him to move on, a place called Y, said they would take him 2 months later they decided they couldn’t and his behaviour deteriorated. These places should NOT, tell someone they can go + then change their minds.’

Some people had been able to move on during this time but were still facing difficulties caused by COVID-19 in their new placement. One carer told us: **‘Glad that my son is now out of the semi secure hospital and making steady progress in the care home he has moved into. Unfortunately, no contact made by any staff from [his care home] with me. [Visits have] stopped and we have not seen each other for 3 months.’**

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Working with staff to co-produce policies around grounds and community leave, as lockdown eases and restrictions change
- Preparing for future possible waves of COVID-19 or local lockdowns with clear communication about any changes as soon as possible
- Being able to talk through any concerns and aspirations about the use of leave.
- Where leave hasn’t been able to progress as a result of restrictions, having other ways to track progress towards discharge.
- For families and carers to be involved in discussions about leave and progress and to be kept updated about any changes.

- Many people told us that effective communication was very important to them – where it worked well for both people in services and their families and carers, it was very reassuring during this time.
- People told us that the use of digital technology was helpful for communicating effectively.
- However, from some of the responses there was at times a lack of effective communication between people in services and staff, between services and families and carers, and in receiving timely and useful updates about COVID-19.

'I have had positive + clear communication from the hospital from my daughter's psychiatrist with him calling me by phone regarding her wellbeing/safeguarding + coping during COVID-19'

Family member or carer of someone in hospital, Q1

Communication as a theme was mentioned:

- **Question 1:** 36 times out of 344 responses – 7th most common themes
- **Question 2:** 13 times out of 333 responses – 10th most common themes
- **Question 3:** 20 times out of 322 responses – 8th most common themes
- **Question 4:** 16 times out of 354 – 8th most common theme
- **Question 5:** 3 times out of 274 – 21st most common theme

Communication intrinsically links with many of the themes that are highlighted in this report. Responses encompassed the practicalities of having the means e.g. digital access, to be able to communicate with those within the hospital in relation to their treatment as well as being able to stay in touch with family and carers within the constraints imposed by COVID-19. There was also the wider need to communicate the updates and changes within the hospital and community due to COVID-19 and the related impact on individuals' day to day life, restrictions and progress. Families and carers, without face to face contact, relied even more heavily on communication about people in services.

What seems to have worked well based on responses was where consistent and structured update meetings took place about the changing conditions due to COVID-19. Some wards had **'COVID-19 weekly meetings to tell us about Government guidelines and discuss what we can do next'** and **'what's happening'**. It was appreciated and valued when staff **'explained things well and kept up to date'**.

One person in a service summarised this by saying **'What worked well was when we were kept informed of the situation and why certain decisions were being made... further decisions were being made for our leave and activities within the hospital. There was good communication again. We (the patients) understood the directives made when there was a good explanation for their justification and reasoning'**.

Some families and carers said they were grateful when they were communicated with well **'I was upset my son hadn't progressed as expected but was kept really well informed and understand the reasons why.'** Alternative ways of communicating with family and carers were most welcomed – **'Zoom meetings (with the hospital) have been very useful for carers to keep up with the current situations.'**

The ability to have continued engagement with community teams was viewed positively with one person in a community service said having **'regular contact with my community team has helped me, either by the phone or video calls'**.

What did not work as well is when there did not appear to be any regularity or **'consistency'** in communicating relevant messaging. There also seemed to be some frustration around contradictions on the ward and staff not **'singing from the same hymn sheet'**.

One carer said that they **'would have liked more information as to what the Mental Health Team have been thinking about treatment, perhaps by video link'**. Some carers said they would also like to see **'regular contact with staff'** continued and for services to look into alternate means of communication e.g. digital/virtual. **'Regular updates on for example visits being reviewed'** would be well received along with **'proactive engagement with carers'**. Some people said they would like services to provide **'regular communication with carers about what's happening in the service'**, with explanations of the **'restrictions that are in place'** and that the processes around these communications be **'co-produced with carers.'**

Others suggested that **'written communication from the hospital each time big changes are made from the government so we can clearly see how they are applying changes within their units would be helpful and appreciated. They would also like to 'continue with regular COVID meetings'**.

One person summarised this theme by saying **'The most important thing is to keep all the patients informed with good communication.'**

Areas for further consideration

People in services and families and carers reflected that the following worked well or may work well in the future:

- Working together to co-produce a communication strategy to ensure clear, regular and up-to-date information about government announcements on COVID-19 so the impact of the restrictions on the services is shared with everyone.
- Include how regular service updates for families and carers will be communicated and in what format.



Digital access

- People told us how much they valued having access to phones and digital devices to enable virtual contact with the outside world.
- However, digital access was not universal across all services, with some services facilitating very limited access or none at all.
- Where there was digital access, some people told us that the processes for their effective use were sometimes problematic and impacted on the quality of their experience.

‘Skype - enables better contact - good for my wellbeing and allows him into my life. ‘Let me see around your house Mum’. I can show him where I’ve put things he’s made for me which I hope means he recognises that he has never been forgotten and he is still in my life’.

Family member or carer of someone in hospital, Q1

As a theme, digital access was mentioned:

- **Question 1:** 59 times out of 344 responses – 4th most common theme
- **Question 2:** 21 times out of 333 responses – 7th most common theme
- **Question 3:** 18 times out of 322 responses – 9th most common theme
- **Question 4:** 36 times out of 282 – 5th most common them
- **Question 5:** 8 times out of 274 – 9th most common theme

Digital access crosses many of the themes in this report – communication, family contact and visits as well as contact with medical teams both in hospital and the community. It was clear there was a marked variability in digital access between services and within individual services.

Those who had the opportunity to use devices to stay in contact with family and carers found it extremely beneficial and **‘comforting’**, and while they voiced their sadness and disappointment in being unable to see their loved ones in person, both family and carers and those in hospital acknowledged that being able to keep in contact and have **‘virtual visits’** was great and really made a difference. Many people were very positive about simply **‘having access to the internet on their laptop’**, being able to **‘use phones in their rooms’** as well as **‘having more internet sessions and access.’**

One carer commented that **‘The virtual visits have been great, it’s very difficult not to hug our loved ones, but to be able to at least see them on the call has been incredibly comforting’** and someone in a service said **‘I want to see family again but video visits are good!!!’**.

Many people said that the use of digital technology was positive and there was a desire to continue this in the future. However, it was clearly expressed that it should be seen as an option or an alternative in the future, not an automatic replacement for face to face contact. It was seen as a welcome addition or development, especially to those families who do not live close to the hospital.

Families and carers said they were very supportive of virtual visits becoming a permanent option going forward, and to allow for more friends and other family members to maintain this type of contact. One person said, **‘the Skype visits are extremely important in terms of ensuring the patient stays visibly connected to the person who supports them, as this helps patient recovery stay on track.’** And that by being able to still have contact with their family member in hospital they **‘still feel actively involved in my son’s care’**.

Some people said that having virtual appointments with their care team was viewed as a positive experience. However, it was expressed that it would be a good addition but not a replacement for face to face consultations going forward. One person said having access to **‘Video teams for clinical meetings, CPAs and managers’ hearings’** was viewed very positively and noted as something that was going well. Continuation of meetings virtually was also mentioned as being very helpful for people living in the community.

The following quotes from people in services summarise the benefits of digital access, but also highlight the need for choice:

‘I am ok to have my doctor on a computer screen during my MDT and CPA’

‘I would rather professionals, like my doctor be in the room for MDTs + CPAs rather than on a computer’

‘Having access to my OT by ‘attend anywhere’ on the computer so that I can see her and talk virtually face to face.’

Some families and carers highlighted frustrations around digital processes and practicalities of access. Even where technology was available, some people said the practicalities around digital visiting didn’t always work well, for example, point of staff contact, adhering to designated time slots, ensuring devices were charged and ready to use and staff members being trained in the use of Skype or FaceTime etc.

In some cases, it took considerable time for wards to get a working device so contact could happen. Some people said that perhaps access to devices was not prioritised enough. One person said, **‘My daughter was booked in for a Skype visit. She received a confirmation email from the reception team informing her of the date & time. She logged in to Skype, was held in the virtual lobby for 15 minutes but was not connected. She rang the ward to inform of the visit, but staff had forgotten. My daughters visit was unable to go ahead.’**

For another person, poor sound quality and the positioning of the device impacted the ability to be able to communicate well, saying **‘There has been a sound quality issue during the Skype visit. The Skype visit is conducted on the ward laptop. The patient can hear me, but I often cannot hear the patient terribly well. I believe it is a problem at ward level on the laptop. It is not a problem on the appliance I use.’**

Another carer told us ‘The arrangements made for parents to participate in meetings [CTM’s etc] were wholly inadequate. I participated in several meetings and found the phone connections dreadful. I couldn’t hear most of what was being discussed, lots of people were talking at the same time and you really couldn’t follow anything going on. The meeting where I was able to Skype was no better; the computer was placed in the board room so far away from where the people sat that you still couldn’t see or hear much clearly. And it took weeks and weeks to get the information needed to Skype with J and I still haven’t managed it as it is difficult to get the ward staff to say when it will be convenient to Skype J’.

Overall, the use of technology to enable people to communicate with each other was overwhelmingly positive to families, carers and people within services and is summarised here:

‘Skype virtual visits have been implemented. This is fantastic because my son & I get to see each other. Visits are once a week. It means I can check if he is alright.’

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Working together with staff to co-produce policies and procedures for the use of devices, ensuring that appropriate practices are adopted to keep people safe.
- Looking to see how services may be able to give people the opportunity to order devices as necessary, taking into consideration any future lockdown measures.
- Undertaking a regular audit of working devices currently available on the ward to help support staff to plan for digital visits/appointments.
- Having the option of virtual visits as a ‘blended’ option for family visits and medical team appointments.



Contact with family and friends

- Where visits and family and friends contact reduced, people in services told us that this was very difficult for them.
- However, where contact was still facilitated virtually, people told us that this had made a positive difference to their experience during this time.
- It was often commented that people in services and their family and carers would like to keep the option of virtual contact as well as face-to-face visits and to have a choice about when to have either – this was especially true for people whose family and friends lived far away.

‘I miss my family and friends like crazy especially my best friend and we need to see those people soon as it is affecting my mental state!’

A person in hospital, Q5

As a theme, contact with family and friends was mentioned:

- **Question 1:** 18 times out of 344 responses – 10th most common theme
- **Question 2:** 83 times out of 333 responses – 3rd most common theme
- **Question 3:** 31 times out of 322 responses – 5th most common theme
- **Question 4:** 4 times out of 282 – 14th most common theme
- **Question 5:** 6 times out of 274 – 15th most common theme

Reduced contact with family and friends

Suspended leave and visits during lockdown have meant that people have been unable to see their family or friends in person. Many survey respondents told us that this had been one of the biggest struggles at this time. One person said **‘I can’t see my mum my family or my dog, I understand the stress of other people not being able to see their family, it just feels like they have been taken away from me. It makes me feel sad. Lonely. It makes me stressed’.**

People told us in response to question 2 that **‘Not being able to see family/friends’** on leave and having **‘no social visits’** or **‘Family visits’** had understandably been difficult at this time. This was true of people in inpatient services and in the community with one person saying: **‘Not being able to see my family and friends who are my support network’.** Someone else said **‘Not being able to see my family or friends, and obviously not being able to hug them or be close to them’** was not working well for them.

In some services, we were told that **‘Each ward has been treated like a household’**, meaning that people on one ward could no longer socialise with friends on another ward. One person said that **‘Not being able to see our friends from other wards when walking around’** was hard for them.

Impact on family and carers

‘Not able to visit at present, but understandable in present pandemic.’
Family member or carer of someone in hospital, Q2

Thirty-nine family members or carers responded to the survey. They reported struggling with **‘Not being able to visit’** their loved one which mirrored the experiences of people in services

above. There was an understanding that this was the safest thing for everyone. One carer said: **‘Missed my family. But understand why’.**

Friendships in secure services

Some people said that lockdown had given them the opportunity to spend more time with their peers on the same ward and build friendships: **‘All the patients have been together playing games... I have been using this time to restore broken friendships on the ward.’**

One person said **‘Being able to bond with patients and staff more’** had been a positive outcome and **‘...spending more time together, interacting more with each other’** had been something good to come out of lockdown.

Digital contact

As already outlined in the Digital Access section, some carers said that staying in touch on the phone or through digital platforms had worked well for them, saying: **‘WhatsApp phone calls with loved ones’** and giving examples such as: **‘Extra Tablets bought in so we can Skype our family and friends’**

One carer said: **‘I am in touch with my son by phone as he is well enough to do this but do not know when it will be possible for us to meet.’** Another told us they felt **‘actively involved’** in their son’s care through **‘Keeping in touch with via telephone regularly’** and having **‘Skype contact as an alternative to visits, including child visits’.**

One carer spoke of their frustration that their **‘relative [is] not allowed to possess a mobile phone’** and another said an improvement at this time would be **‘better access to Skype calls to family’.** However, another carer said they had enjoyed the **‘regular phone contact with relative. Live far away so this works for us.’** This could be a move supported by many carers of people who are placed at a distance from their home area.

Lockdown easing and moving forward

‘If people in the community can go out and see people from a safe distance why can’t we?’

A person in an inpatient service, Q3

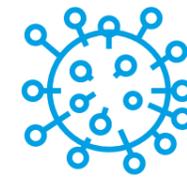
Some people who submitted survey responses after government lockdown easing measures were announced expressed frustration that people in the community were now able to see friends and family but that visits and leave in their service had not restarted. One person told us that not **‘being able to see family as lockdown eased’** was not working well for them.

However, in other services visits had been reinstated quickly and people told us that this had been a positive change with one person in an inpatient service saying **‘I miss my family but now visits are happening its good’.**

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Informal peer-to-peer support and relationships encouraged through socially distanced activities.
- Working together with staff to co-produce policies to support people to stay in contact with family and friends.
- Virtual visits and digital contact with family and friends to continue, beyond COVID-19, where services have these mechanisms in place.



Preventing the spread of COVID-19 in secure services

- Overall, people told us they were very understanding of the measures that needed to be in place to limit the impact of COVID-19 and keep them safe.
- Some people told us that they would value some of the measures, such as social distancing and increased hygiene, to remain in place for some time to come.

‘I know the staff are putting in the right procedures to control the virus, so at least with all my other problems, I don’t have to worry about this’

A person in hospital, Q1

As a theme, infection control measures were mentioned:

- **Question 1:** 70 times out of 344 responses – 3rd most common theme
- **Question 2:** 87 times out of 333 responses – 2nd most common theme
- **Question 3:** 46 times out of 322 responses – 3rd most common theme
- **Question 4:** 54 times out of 282 – 3rd most common them
- **Question 5:** 29 times out of 274 – 4th most common theme

One of the biggest changes to life in secure services has been the infection control measures brought in to prevent the spread of COVID-19. This section of the report overlaps with other themes such as Outdoor Access, Leave, Physical Health and Staff, and was an important issue to respondents.

The survey found that people in inpatient services were worried about catching the virus. One person told us that their **‘Anxiety levels have gone up with a real fear of getting covid especially as I have underlying health conditions...’**

Some people told us that they had confidence in the measures put in place in their service, with one person telling us there had been **‘A careful & responsible approach tackling COVID-19’.** While another said there was a **‘...reassurance that all safety precautions have been taken and that the staff have been very helpful.’**

There was also an understanding of the importance of protecting others through the measures taken, with one person telling us that **‘...the hospital is under pressure with COVID-19, so I am happy to do what I can to help’** and another that they have **‘...been happy to follow the guidance so not to pass on the virus to anyone else.’**

The survey revealed that people thought there was a difficult balance to achieve between processes to prevent the spread of the virus and supporting people’s mental wellbeing and recovery, especially as lockdown eases and people in the community are allowed more freedoms.

Which infection control measures have been working well in services at this time?

'The nurses Have been in control of the situation on the ward'

A person in hospital, Q1

Some people said that the infection control measures had worked well in their service. One respondent told us **'The hospital had done all they can'**.

A carer shared a similar experience, saying **'Protective measures at the hospital seem to have kept infections low, well done'**.

A range of different ways to prevent or halt the spread of the virus were mentioned in survey responses as working well:

Restrictions and Isolation

As outlined in the Outdoor Access, Leave and Family Contact sections of the report, some people said that **'being indoors'** and **'staying inside'** and restricting leave was working well to stop the spread of the virus.

One person told us **'Being isolated has been good because it has protected us from catching the coronavirus'** and another informed us that more vulnerable service users who needed to shield were being **'well looked after'**.

Testing positive for COVID-19

People that had **'tested positive for COVID-19'** said they were looked after well with one person saying **'I was treated very well and obviously made a tremendous recovery'** and another was grateful to have recovered **'I caught the epidemic and got over it so I am happy'**. This was also highlighted by a carer whose son had caught COVID-19 and was **'...very well looked after and said himself that the staff could not have done more for him which is praise indeed from a patient'**. Another person said: **'Everyone did a fantastic job containing the spread of the virus from people who tested positive'**.

Personal Protective Equipment (PPE)

'Masks are working well'

A person in hospital, Q1

There was anxiety from some people about COVID-19 being brought into hospital from staff, with one respondent saying **'...staff are the ones bringing the virus in, we aren't allowed out'** and another person saying **'...staff are in contact with the COVID-19'**. Many people seemed reassured though by the Personal Protective Equipment (PPE) in use in their service and with **'Staff taking extra precautions'**.

There was some anxiety noted around the way PPE, especially masks, looked on people, and this is outlined in the **'What isn't working well'** section below.

Hygiene

Some people in inpatient services told us that personal hygiene and hand washing had improved from pre-COVID-19 standards and that this had been a positive change. One person said that **'...the heighten standards of hygiene have been very reassuring'**.

One respondent said they had been washing their hands **'...more than usual'** and another remarked that the overall **'Cleanliness had been good'**. People also said they hoped **'Such things as cleanliness and hygiene'** would continue in the future.

We were told that staff had supported with this and made sure that people were washing their hands more frequently with one person telling us that **'Staff keeping us safe and ensuring we wash our hands regularly.'**

A carer also told us that they were pleased that there was **'...hand sanitiser provided'** for patients, people working in, and visiting a secure service.

Which infection control measures have not been working so well at this time?

Social distancing

'Social distancing is not realistic in hospital and very hard to achieve'

A person in hospital, Q4

Some people told us that **'Social distancing'** had not been working very well in their service with one person saying there was **'A clear lack of social distancing for much of the time'**.

There was a call from one respondent for staff to be more **'pro-active'**, and make sure that patients, people working in, and visiting services were aware of and keeping to the social distancing rules.

Some people said it had worked and they wanted to **'Keep social distancing a priority'** in their service even as lockdown eases.

Masks

‘Sometimes the staff can look intimidating with masks on like Halloween’

A person in hospital, Q2

Some people said that the masks used by staff were scary, strange or intimidating, with one respondent telling us: **‘it scares me with the masks’**. Another person stated it was **‘something like out of Star Wars with the PPE’**.

Some people said they had **‘not been given masks’** and would feel safer if had. Another person said, **‘I have found it difficult because wearing the mask I didn’t like wearing it’**.

COVID-19 Testing

‘[More] Frequent tests for COVID-19’

A person in hospital, Q3

A few people said they had been tested after developing the symptoms of COVID-19 with one person saying that **‘Being tested and being negative was a mind reliever.’** Some people told us that they would like to see more **‘Prompt testing’**.

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Working together with staff to:
 - Agree a balance between maintaining infection control measures to help keep people safe and easing restrictions in order to support people’s wellbeing.
 - Agree how lockdown easing in the community can be safely reflected in their service in a timely manner and communicated to everyone.
 - Coproduce policies for implementing social distancing measures taking into account ward size and layout.
 - Co-produce communications for people in inpatient services around the use of masks.
 - Ensure the use of PPE is not triggering, scary or incompatible with a recovery-centred environment e.g. using clear masks or having staff pin photos of themselves on their jacket so people can see their face and working one on one with people who are afraid.
- Continuing certain infection control measures, such as increased hand hygiene, to maintain the quality of the living environment and prevent spread of other illnesses.
- COVID-19 tests being readily available to patients and those working in services.
- Continuing to inform families and carers and people on the ward if someone has tested positive for COVID-19 and keeping them updated on their recovery.



Physical health

- We linked a broad range of different responses into the theme physical health – for example, managing a healthy weight, physical activity, diet, smoking, e-cigarettes and sleep.
- People told us about having both increased and decreased access to physical activities, with a detrimental effect on their physical health and wellbeing.
- There was marked variability in smoking policies across services, with some people telling us that they were able to use e-cigarettes in their room and others telling us that they were unable to smoke at all during lockdown.

Physical Health was felt to be a very important theme based on the recent DHSC Obesity Strategy, where being obese was found to be a risk factor of dying from COVID-19². In addition, COVID-19 is a respiratory illness and smoking tobacco and e-cigarettes is thought to increase vulnerability to the illness³.

As a theme, the different aspects of physical health discussed here were mentioned:

- **Question 1:** 44 times out of 344 responses – 5th most common theme
- **Question 2:** 39 times out of 333 responses – 5th most common theme
- **Question 3:** 32 times out of 322 responses – 4th most common theme
- **Question 4:** 13 times out of 282 – 9th most common them
- **Question 5:** 9 times out of 274 – 7th most common theme

In their survey responses, some people in services told us that rules around smoking, diet and physical activity had changed during lockdown, becoming on one hand more restrictive and for others more relaxed.

Some people said that access to gyms and outside physical activity had been restricted due to restrictions on grounds and section 17 leave. Others told us that they had been having an increased number of takeaways during this time and that there had been a relaxation in the rules around e-cigarettes and smoking.

² DHSC (2020) ‘Tackling Obesity: empowering adults and children to live healthier lives’

³ Action on Smoking and Health (2020) Quit For COVID-19 campaign

Managing a healthy weight during lockdown

Public Health England's 2016 report on Obesity in Adult Mental Health Secure Units showed that the prevalence of obesity in patients in secure care is two to three times higher than the general population⁴. Whilst many secure services have been taking steps to support people to achieve and maintain a healthier weight, following the NHSE/I Draft Managing a Healthy Weight Practice Guidance and accompanying Recovery and Outcomes report⁵, we stress the need to continue implementing these despite the challenges arising in the new COVID-19 context.

Physical Activity and Exercise

'Being able to spend time in the garden and in the ward gym has helped us cope with the lockdown.'

A person in hospital, Q1

As outlined in the Outdoor Access and Activities section of the report, the variability between wards and within services around access to physical activity during lockdown differed greatly. Some people in inpatient services told us:

- They had been able to exercise in the grounds during this time.
- They had been unable to go outside to exercise and listed this as an improvement they would like to see. For example, one person said 'Going out to do more exercise' would be an improvement and another wanted a plan for 'accessing secure gardens for activity & fresh air'.
- They had been allowed out '...to go for walks as lockdown restrictions have lessened'.
- They had been enjoying ward-only gym time, where a limited amount of people from one ward could visit the gym at one time, with thorough cleaning between visits.
- They did not have access to the gym and wanted to go back to having the gym 'everyday'.

Encouragingly, some people said they had been self-motivated to do exercise in their bedrooms which had supported them during this difficult time, with one person saying, 'I have been doing exercise in my room, it has been helping with my anxiety.'

Diet

'Look forward to meal-times – food is good'

A person in hospital, Q1

Some people in inpatient services told us that food had been a source of comfort and 'meal-times' had provided a sense of routine and continuity from life pre lockdown. They said they had appreciated food arriving 'on time'.

One person told us that the food in the service was 'good and healthy' and they wanted this to continue after lockdown but treats like 'eating chocolate' had also been welcomed. Food, like ward activities and e-cigarettes, seems to have acted as a comfort and a distraction at this time. However, another person flagged that this had led to them overeating, saying: 'I think we are on the ward 24/7 for so long, is not good. Because we eat more every day.'

As reflected in our recent Recovery and Outcomes report 'Feedback on the Draft Managing a Healthy Weight Guidance'⁶, food quality differs across services. Despite some people describing the food in their service as good, one person told us the food in their service was 'terrible' and another said the quality had 'gotten worse' during this time.

In some services, people told us the social and community element of dining had been lost as people had to eat in their bedrooms to ensure social distancing. For example, someone told us that 'Not being able to eat meals in the dining room' had not been working for them at this time. Another person said that having 'Food in canteen' was an improvement they would like to see.

There was variability in the survey responses around takeaways, with some people in inpatient services saying that the number they were allowed a week had increased. One person said that the 'Ward manager lets us have two takeaways a week' and another wanted to 'Continue to have two takeaways a week'. However, others told us that there were now 'no takeaways' and that they '...wish that during Covid we could get takeaways weekly'.

Due to restrictions around leave, some people told us that they had been unable to go out to the supermarket. Others said they had found the ward and tuck shops to be a good alternative during this time, with one saying that 'The tuck shop increases allowances and opened twice a week, so we still had goodies'.

Tobacco smoking and e-cigarettes

'We want e-cigarettes'

A person in hospital, Q2

Many people told us that access to smoking had been very restricted during lockdown. Some people lamented that they had not been able to smoke at all and there had been a 'E-cigarette ban', others reported tighter restrictions to where and when they could smoke due to social distancing or suspended ground leave.

People seemed to miss the routine and social element of tobacco smoking and vaping as well as it being a good way to '...pass the time and deal with stress'.

In contrast, some people who responded to the survey told us that since lockdown, they had experienced more freedom around e-cigarette use and smoking. For example, one person told us they had enjoyed 'Unlimited e cig use and been able to use this in my bedroom'.

⁴ Public Health England (2016) Working Together to Address Obesity in Adult Mental Health Secure Units

⁵ Rethink Mental Illness (2020) Draft Managing a Healthy Weight Guidance Feedback from people in low and medium inpatient secure services

⁶ Rethink Mental Illness (2020) Draft Managing a Healthy Weight Guidance Feedback from people in low and medium inpatient secure services

Sleep routine

'I can't sleep well'

A person in hospital, Q2

One person told us they were **'Sleeping a lot'** as they **'would like to have something to do.'** Another person told us that they were struggling with **'Arising on the AM'**.

Routine is important especially during lockdown when leave and visits have been cancelled and if there are fewer activities. But oversleeping could be due to boredom reported by many: **'Being in lockdown can be very boring'**.

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- Working together with staff to coproduce:
 - Policies and procedures to ensure that the new Managing a Healthy Weight Guidance is adapted to a COVID-19 context.
 - Ward-based smoking policies that take into account both the service's smoke-free policy as well the wellbeing of people in their service during this time.
- Offering one form of physical activity daily minimum – whether this is in an outside space, in the grounds or in the gym, with social distancing enforced as needed.
- Reviewing food quality and co-producing menus as recommended in the newly published Managing a Healthy Weight Guidance. Including:
 - Considering healthier 'fakeaway' nights, rather than takeaways.
 - Ward shops continuing to stock a range of items including healthy alternatives.
- Where safe to do so, encouraging communal dining to foster a sense of community on the ward.



Staff

- A common response related to the value people placed on staff support and kindness during this time.
- People said how grateful they were to staff for helping them to stay safe and well.
- There were some responses that told us that there had been reduced staffing levels, and that this was sometimes linked to difficulties on the ward.

'Everyone is in this together- service users and staff and we have come together to understand the challenges that everyone is facing- it felt like we were working as a team through a difficult time'.

A person in hospital, Q1

As a theme, staff were mentioned:

- **Question 1:** 104 times out of 344 responses – most common theme
- **Question 2:** 15 times out of 333 responses – 9th most common theme
- **Question 3:** 26 times out of 322 responses – 6th most common theme
- **Question 4:** 53 times out of 282 – 4th most common them
- **Question 5:** 62 times out of 274 – 2nd most common theme

Gratitude from people in services, family and carers for staff kindness and support came across overwhelmingly in the survey. **'Staff have also been supportive with us, talking to us, listening to us, has brought our mood up'**. People have felt that **'quality time'** with staff has enabled them to **'bond more'**:

'I like it cause I can always talk one to one and speak what's on my mind any time.'

People told us that staff have been focused on their wellbeing and **'continue keeping us safe and understanding when we are feeling down and to continue supporting us.'** One person told us that **'I have managed to control myself and not self-harm. I listen to staff to remove myself from stress.'**

Empathy for staff from people in services was highlighted throughout the responses of the survey: **'Staff have been scared too and we can tell, it is to be expected, it has raised my anxiety a little bit, but we have all talked and used distraction together, and it helps knowing the restrictions are justified and that worrying is normal'**.

However, some people said that at times **'staff levels get low'** and that there is **'not much consistency with regular staff. Because you build relationships with staff and trust and if they are not around it can affect you mentally.'** The issue of short-term agency staff was evident at times during the pandemic based on the responses.

The impact of COVID-19 on staff was at times observed by people in services with one person saying **'Sometimes that staff can get a bit stressy. You can tell the whole thing is effecting people mentally.'** Also, some insensitivities whilst on the ward emerged such as **'staff complaining how bored they are at home when we are stuck in a unit wanting to be home'**.

Some people felt that they were not engaged with sufficiently by staff at certain times **‘maybe staff could talk to us if we look upset and were not given the opportunity to discuss ideas or feedback on changes or processes’** suggesting that staff might want to start **‘listening to the patients when they have ideas and for patients to give feedback ... About how we are doing as a team’**.

Overall, however, staff gratitude came through consistently, with people saying:

‘The staff have been a massive support network whilst on lockdown’

‘The work from the care team is Fantastic in this difficult times I give ***!! (5 stars) To all’**

‘A big thank you to all the support and keeping us going through the hard time.’

Areas for further consideration

People in services reflected that the following worked well or may work well in the future:

- There was huge gratitude towards staff.
- There seems to be a real opportunity to build on the unity, improved relationships and feeling of solidarity during this time to encourage and support more open communication and effective co-production.
- Supporting staff to receive training on the relational aspects of their work including emotional awareness, supporting resilience and active listening skills could be very beneficial within services.
- Having a lead that focuses on the wellbeing of people in their service and their families and carers could be beneficial for all.

Other themes

The marked variability in responses also comes across in the themes that did not fit into the nine main themes analysed above. In terms of unique themes there were:

- 31 in question 1;
- 25 in question 2;
- 29 in question 3;
- 28 in question 4;
- 38 in question 5.

People have had both a variable experience of COVID-19 and also different personal responses to the pandemic. For example, one person living in the community simply said, in their response to question 5, anything else you’d like to tell us, that **‘it is awful’**. There were no other details in the response, but it is clear that they have found the experience very difficult. In contrast, people in hospital have commented **‘I feel well and safe’** and have said they show **‘Gratitude and thanks, a general sharing of humanity’**.

One person told us **‘I have been happy with the way everything is being dealt with’**. Another person described stoicism amid adversity, saying **‘Keep plodding along. Chin up, chest out, show them what it’s all about’**. Another said **‘It’s a sad tragic thing worldwide. People here in the hospital are trying their best to get through. It’s nobody’s fault.’** Similarly, one person said:

‘Despite what we had to endure it has been nice to see the togetherness in the battle against Covid. Some lovely stories shared, and relationships formed. I think staff has been excellent and so brave and I hope we all will continue to show those people that appreciation. It’s also been nice to slow down and pay attention to some things we take for granted or may not have done for a while. To be honest, a bit of an eye opener for me.’

Other people in services commented:

‘Working with the lads, and how all the patients have muscled in together to support each other and have shown a good attitude and it is nice to see. I have been happy with the way everything is being dealt with.’

‘Everyone is working hard; we are working together as one team – we can do this if we stay together and be brave: “COVID 19 CANNOT BEAT US!”’

However, another person commented more widely on the implications for people in secure care, saying **‘The government don’t seem to be addressing the issue of detained patients, there was bits about those who are treated under the Capacity Act and allowing them family support in hospital, but not about those under the MHA.’**

When telling us what else they would like to share about their experiences of COVID-19, one carer said **‘Families often feel isolated from mainstream society. Due to COVID-19 a lot of members of the public have felt cut off from society itself, their family & their friends. To be perfectly honest, as a High Secure Carer this was my life experience before COVID-19. I have felt like saying.....welcome to my world of isolation. I think it goes some way for members of the public who have felt isolated & loneliness to perhaps have a degree of empathy for those of us linked to a Secure Hospital. I think it would be a good example to use within training sessions for all Mental Health disciplines.’**

Summary of questions 4 and 5

Questions 4 and 5 were the questions that attracted the fewest responses. For many responses to question 4 it seemed that people were responding about what they would like to see happen in the future, rather than what was happening now that they would like to see continued. For this question:

- 26 people said **'nothing'**
- 5 people were **'unsure'**
- 86 surveys were left blank.

The other responses that were given to these questions have been accounted for within each theme of the report. A breakdown of responses by theme shows that the most common things that are happening now that people would like to see continued are:

- **Increased and more varied activities, on and off the ward, especially gym access**
- **Increased staff support – including numbers of staff, quality time spent with them and the kindness that has developed during this time – 'a greater sense of togetherness'**
- **Infection control measures, including social distancing and personal hygiene**
- **Digital access – with a choice of when and how they are used:**
 - For contact with family and friends
 - For online shopping
 - For meetings, such as MDT, CPAs, Tribunals
- **Better communication – information sharing with people in services, with family and**

friends and between care teams

- **Increased outdoor access**
- **Improved progress towards discharge**
- **Better food – cooked on the ward and access to self-catering**
- **Increased, more easily accessible community support**

For question 5:

- **135 responses to this question said 'nothing' or were left blank.**

We have included responses that relate to one of the themes of the report within those. Other responses to this question include:

- **The importance of community team contact**
- **Feeling 'stressed' and 'daunted' by COVID-19**
- **Feelings of 'doing well'**
- **The importance of faith practices**
- **Requests for more peer support**
- **The importance of comfortable visiting facilities**
- **The positive benefits of new-build environments – increased space and lighting**
- **The impact of news and media**
- **The enjoyment of the 'clap for carers' and 'Captain Tom's fundraising'**
- **A desire for a return to 'normality'**

Acknowledgments and thanks

In compiling the survey, we are grateful to all of the Experts by Experience who helped shape the questions and information sheet.

We are also grateful to the Rethink Mental Illness Oxfordshire Carers Service for facilitating the return of postal surveys.

Finally, we are indebted to everyone who took the time to complete the survey and to all the staff in adult secure services around the country who distributed, collected, scanned and emailed or posted all of the surveys back to us.

APPENDIX ONE

Example Information Sheet & Survey

Adult Secure service user, family and carer feedback survey about your experiences during coronavirus (COVID-19)

We would like to ask for your help! The views of people in secure services and their families and carers really matter to us and we would like to give people the opportunity to share their views about the lived experience of people in adult secure services or in the community, as well as their families and carers during this time with COVID-19.

What we are doing and why

As part of the Recovery and Outcomes Network for adult secure services, we're always keen to hear from people living in secure services. While our regular Recovery and Outcomes Groups are unable to take place, we've created a survey as we'd really like to hear how service users and their families and carers are getting on during this difficult time.

We're working with NHS England and Improvement (NHSE/I) to find out what is working well for service users, families and carers, what is not working so well and what improvements people would like to see during this time.

We'd also really like to hear about the things that are happening now that people would like to see continued in the future. All of this information will really help NHSE/I and providers of secure services for future planning.

We understand how busy people must be during this difficult time, but we would be very grateful for your help. **Please reply by Wednesday 17th June at 12noon.**

We would like to hear from service users, families and carers in all adult secure services – high, medium, low and community services.

We would be grateful if you would answer the following questions in as much detail as possible – all of your feedback will be very helpful. You can complete the survey either individually or as a group.

All of your answers are anonymous, and we will only contact your service if you tell us anything that puts you or other people at risk.

The Survey

Thinking about the last three months and all the things that have happened as a result of COVID-19:

1. What has been working well for you during this time?
2. What is not working so well?
3. What improvements would you like to see?
4. What is happening now that you would like to see continued in the future?
5. What else would you like to tell us about or share with us at this time during COVID-19?

We would like to make sure that we receive responses from across England and so it would be very helpful if you could tell us the name of your service (but this is optional) or even where in the country your service is in, and to let us know whether you are someone who is currently in a secure hospital or in the community, or a family member or carer.

Name of service or area of the country

.....

Which of the following best describes you or the person answering the questions:

- Service user(s) in hospital
- Service user(s) in the community
- Family member or carer of someone in hospital
- Family member or carer of someone in the community
- Other (please state).....

APPENDIX TWO METHODOLOGY

How to reply

There are **three ways to send responses to us:**

1. Email your responses to me at: recoveryandoutcomes@rethink.org
2. Print this survey and return the completed forms by email to: recoveryandoutcomes@rethink.org
3. Complete the survey online by clicking [here](#). Please note that you will need to register to the site to access the survey, but once you register, you will have access to a wide range of resources and forums related to Mental Health and Learning Disabilities and Autism during COVID-19. If you need help to register please contact england.sc.mh@nhs.net.

Thank you

We really appreciate your time in sharing your views with us – we will be collecting together all the responses and will produce an overview to inform key discussions and future planning at NHSE/I. This will help us to ensure that the voice of people in secure services and their families and carers can influence how services are run, now and into the future.

We would like to stay in touch, so please let us know how best to contact you if you would like to receive updates later in the year on how this information has been used.

Many thanks and with best wishes,

Ian Callaghan
Recovery and Secure Care Manager
Rethink Mental Illness
recoveryandoutcomes@rethink.org

During May 2020, in collaboration with NHSE/I and in consultation with a group of Experts-by-Experience who work regularly with the NHSE/I Specialised Commissioning and Secure Care Programme teams centrally, we co-produced a survey to gather the views and experiences of people in secure services, families and carers (both in hospital and the community) on the impact of the Coronavirus (COVID-19) pandemic. We developed a survey and information sheet (Appendix One) to explain why we were doing this, how the information would be used and how to contact us if people wanted any further information. Through co-production we decided to have only a few, open-ended questions to gather principally qualitative information, that we believed would be as accessible as possible to the most people in secure services, together with their families and carers.

We asked people to answer the survey questions in as much detail as possible – we stressed that all feedback would be very helpful. It was decided that people could complete surveys either individually or as a group and to indicate where this was the case. We asked people to tell us whether they were someone in an inpatient service or in a community service and whether they were a family member or carer of either of these groups. We also gave people an option of providing either the name of their service or the geographical area but not ward, in which they were located, to give us an idea of representation across services and geographical spread. We made it clear that the survey answers would be anonymous and that we would only take action if someone told us anything that put themselves or other people at risk.

The survey asked people to think about the last three months and all the things that have happened as a result of COVID-19 and tell us:

- 1. What has been working well for you during this time?**
- 2. What is not working so well?**
- 3. What improvements would you like to see?**
- 4. What is happening now that you would like to see continued in the future?**
- 5. What else would you like to tell us about or share with us at this time during COVID-19?**

The survey was distributed at the end of May and sent out by email to the Recovery and Outcomes mailing list, which reaches most secure services, and via NHSE/I regional teams to all contracted adult secure providers, the Adult Secure Clinical Reference Group and the Adult Secure Provider Collaborative Clinical Forum. In addition, an online survey using the same questions was created on the FutureNHS Collaboration Platform, which was advertised by blog posts and other posts on the platform. The survey opened on 27th May and closed on 17th June.

The survey was formatted to give space for handwritten responses, or it could be completed electronically in Word. Almost all surveys were completed by hand, mainly by people in services themselves, family and carers, with a few completed with support from staff. We also received some responses from staff themselves – these do not form any part of the analysis. Most of the responses were returned by staff directly as scanned completed copies of the survey form to the Recovery and Outcomes team email inbox. Some people chose not to use the form, but to indicate the question number and response in a separate document. A few people asked for copies of the survey to be posted to them and to return them by post, which was facilitated by a Rethink Mental Illness service and then forwarded on to the Recovery and Outcomes team.

On receipt of a completed survey, they were allotted a response number and saved securely. Where respondents did not give a service or geographical area, while it was often clear from email signatures where the response originated, this was not recorded or included in the statistics given below. All of the completed surveys were then reviewed and analysed by two members of the Recovery and Outcomes team, who agreed on the themes in response to each question, inputted them into a spreadsheet and recorded some of the responses verbatim for quotes to be used in this report. Themes were developed iteratively based on the responses gathered, with some sub-themes ascribed to ensure that nuanced responses were captured. In this way, we were led in the analysis by the voice of the respondents themselves, rather than by a pre-determined list of the themes we thought we might expect.

APPENDIX THREE OVERVIEW OF STATISTICS

We received 368 responses in total, with only one of the responses coming from the FutureNHS Collaboration Platform survey.

Table 1 gives a breakdown of the number of responses by type of respondent and their geographical area. Below each geographical area, we have indicated the number of services that were named by people within that geographical area. We have also given the number of responses that left the name of their service or their geographical area blank.

The number of responses by theme and by question is given in Table 2 and these have informed the themes that have been most closely analysed.

Table 1: Number of responses by type of respondent and geographical area

Geographical Location of Service	Total Responses	Service User Hospital	Service User Community	Family / Carer Hospital	Family / Carer Community
East Midlands (5 services)	30 (1 staff)	27	1	1	0
East of England (5 services)	63	51	9	3	0
London (7 services)	46 (1 staff)	42	0	3	0
North East (1 service)	1	0	0	1	0
North West (6 services)	58	52	0	5	1
South East Coast (2 services)	7	6	1	0	0
South Central (3 services)	23	20	0	2	1
South West (4 services)	17 (1 staff)	14	1	0	1
West Midlands (3 services)	6 (2 staff)	4	0	0	0
Yorkshire and Humber (4 services)	29 (1 staff + 1 not specified)	9	0	18	0
No Service recorded	185				
No area recorded	88				

Table 2: Number of responses by report themes and question number

Q1 (344 responses)		Q2 (333 responses)		Q3 (322 responses)		Q4 (282 responses)	
What is working well for you?		What is not working so well?		What improvements would you like to see?		What is happening now that you would like to see continued in the future?	
Staff	104	Leave / Progress	120	Leave / Progress	93	Activities	56
Activities	79	Infection Control Measures	87	Activities	59	Infection Control Measures	54
Infection Control Measures	70	Family Contact	83	Infection Control measures	46	Staff	53
Digital Access	59	Activities	49	Physical Health	32	Digital Access	36
Physical Health	44	Physical Health	39	Family Contact	31	Leave / Progress	18
Communication	36	Digital Access	21	Staff	26	Communication	16
Outdoor Access	24	Outdoor access	16	Communication	20	Physical Health	13
Family Contact	18	Staff	15	Digital Access	18	Outdoor Access	9
Leave	16	Communication	13	Outdoor Access	17	Family Contact	4



**Leading the way to a better quality of
life for everyone severely affected by
mental illness**

For further information
on Rethink Mental Illness
Telephone 0300 5000 927
Email info@rethink.org

www.rethink.org