

Minister for Mental Health

Clare Haughey MSP



Lewis Macdonald MSP
Convener, Health and Sport Committee
Scottish Parliament

2nd October 2020

Dear Lewis,

Report by Dr Nadine Cossette into mental health needs of patients hospitalised due to COVID-19

Earlier this year, the Scottish Government commissioned Dr Nadine Cossette, a liaison psychiatrist from the Royal Infirmary Edinburgh, to examine mental health needs of patients hospitalised due to COVID-19. Dr Cossette has extensive experience working directly with COVID-19 patients and has developed a new patient pathway in NHS Lothian to enable earlier psychiatric assessments.

Dr Cossette has now produced her report and I am writing to share this with the Committee. A copy will also be placed in SpICE. Principal conclusions include:

- The effects of severe COVID often continue after the patient leaves hospital. Approximately one-third of COVID patients admitted to hospital develop serious mental health consequences, including depression, anxiety, PTSD, and cognitive problems.
- Additionally, complex multifactorial presentations known as 'long COVID' are being recognised as very significant and distressing consequences.
- Data is starting to emerge on broad outcomes after hospital admission for COVID which confirms this. A large UK prospective study has just reported on COVID outcomes 12

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weeks after hospital discharge. 74% of patients had persistent symptoms, especially breathlessness, fatigue, and insomnia, despite a low rate of persisting clinical abnormalities.

Dr Cossette recommends a range of proposals including a network of COVID mental health clinicians across Scotland, fully integrated into bespoke, multidisciplinary rehabilitation teams. She also proposes that this should be supported by a national network, development of a clear and personalised national digital platform for COVID recovery, and expansion of peer support.

The Scottish Government welcomes this authoritative report. It contains helpful data on mental health needs of hospitalised COVID-19 patients and makes a strong case for a range of actions to assist their recovery. We are supportive of the recommendations and, with that in mind, we will consult with Boards on how best to implement this report. A number of the recommendations relate to service reconfiguration, so work is required to ensure that proposals are fully costed and can be implemented locally. Consideration must also be given to how best to link new proposals with existing services and the lifespan of any new services. In order to take this work forward, Dr Cossette has kindly agreed to chair a short life working group tasked with implementation of this report.

I am pleased to confirm that funding has been approved to support Dr Cossette's recommendation to expand peer support, subject to Spending Review. £187,534 will be awarded over two years to the charity ICUsteps to establish and run additional patient-led peer support groups across Scotland, in collaboration with the Scottish Intensive Care Society and University of Dundee. I can also confirm that £128,000 additional funding has already been provided to Cruse Bereavement Care to help ensure that there is an increased capacity to support those who have lost loved ones during the pandemic.

I hope that this is helpful and I will keep the Committee informed as this work develops.

Yours sincerely,

CLARE HAUGHEY

Enc. Report by Dr Nadine Cossette.

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Meeting the Mental Health Needs of Patients Hospitalised Due to COVID-19

A Plan for Scotland

September 2020



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Meeting the Mental Health Needs of Patients Hospitalised Due to COVID-19

A PLAN FOR SCOTLAND

DR NADINE COSSETTE

In July 2020 Dr John Mitchell, then Scottish Government Mental Health Directorate Principal Medical Officer, commissioned the author to assist in the development of support for patients hospitalised due to COVID-19, particularly those who spent time in ICUs. The aim was to make practical recommendations for a focussed national care pathway for local interpretation to meet the mental health needs of people going through acute hospitals, with follow up as appropriate in the community.

This report specifically addresses the needs of patients hospitalised due to the virus in line with the original commission and given the particular circumstances experienced in a hospital setting. However much of the analysis and some of the recommendations will be equally relevant for patients treated in the community.

As of 22 September 2020, 4,347 patients had been discharged from hospital in Scotland for COVID, including approximately 570 from ICU.

Executive Summary

The effects of severe COVID often continue after the patient leaves hospital. Up to one-third of COVID patients admitted to hospital develop serious mental health consequences, including depression, anxiety, PTSD, and cognitive problems. Additionally, complex multifactorial presentations known as 'long COVID' are being recognised as very significant and distressing. Given the scale of the COVID pandemic, this increased health burden will have a significant impact upon Scotland's mental health services.

Mental health services in Scotland are not currently configured to meet these needs, nor do they have the capacity. The mental health consequences of COVID are interwoven with its physical complications, making specialty-based follow-up services not well suited to meet the needs of these complex issues.

The rapid creation of a network of COVID mental health clinicians across Scotland, fully integrated into bespoke, multidisciplinary rehabilitation teams, will allow Scotland to make best use of existing resources to meet this need.

This should be supported by the establishment of national specialist advisory group, the development of a clear and personalised national digital platform for COVID recovery, and the expansion of peer support.

Scotland has excellent mental health resources. These recommendations will enable them to be used in an agile and person-centred way to allow early access to expert care for patients recovering from this complex and new condition.

Meeting the Mental Health Needs of Patients Hospitalised Due To COVID-19: A Plan for Scotland

COVID-19 is a multisystem disease that can have significant effects on mental health and wellbeing. As we move to the next stages of managing the pandemic, it is imperative that patients across Scotland who have suffered severe COVID illness have access to the right mental health care at the right time.

Experience of Severe COVID

Admission to hospital with COVID can be a frightening experience. Patients report feeling helpless, fearful and vulnerable. They find themselves in strange and confusing environments, interacting with staff in full PPE, and separated from loved ones due to visiting restrictions. Patients are often aware of fellow patients around them dying and many fear they themselves will not survive. Treatments such as ventilation hoods can cause a sense of suffocation and panic. Delirium, causing confusion, hallucinations and delusions, occurs in up to 70% of ICU patients (Marra et al 2017), and appears to be particularly frequent and severe in COVID (Helms et al 2020).

Returning home following a hospital admission with COVID can also be a distressing experience. Patients face uncertainty regarding their medical prognosis, and discharges during lockdown can leave patients feeling isolated and distanced from their usual sources of purpose and pleasure. Many are concerned over their family's distress. Many have suffered bereavements while they themselves were ill. Financial strain and uncertainty are magnified by concerns about ability to return to work.

Family members and carers also suffer high degrees of strain when loved ones are hospitalised for COVID, hearing distressing news by telephone, seeing videos of their loved ones appearing moribund and being unable to comfort them, and enduring all of this while themselves being in lockdown and away from supports. Many experience terrible shock when seeing how weak and unwell their loved ones are on return from hospital but do not feel able to speak about their own distress. Mental health services need to address their needs as well.

Mental Health Effects of COVID

While the majority of patients will recover from these experiences, some will develop persisting serious mental health disorders. Anxiety, depression, and PTSD are known to affect 40, 30, and 20% respectively of patients after any ICU stay (Hatch et al, 2018). After the 2003 SARS outbreak these effects were found to be long-lasting, with 25% still suffering PTSD after 2.5 years (Mak et al, 2009).

Evidence with COVID is beginning to emerge. A recent Italian study found 56% of patients screened positive for at least one mental health problem after one month

(Genarro Mazza et al, 2020). An important finding was that mental health outcome inversely correlated with length of admission.

In Lothian, we are contacting all patients who were hospitalised for COVID three months after discharge to invite them to complete measures of distress, trauma, and cognition. 36% of patients have screened positive on at least one of these measures. Patients discharged from ICU were not more affected than patients discharged from other wards, and patients discharged from ICU but seen in hospital by psychiatry had lower rates than either other group.

UK neurological and neuropsychiatric national surveillance data (Varatharaj et al, 2020) shows that a small number of COVID patients will experience direct neurologic involvement such as encephalitis, stroke, and guillain barre syndrome, however it looks like these direct complications are rare. Far more frequent are nonspecific symptoms such as fatigue and cognitive fogging, complex presentations which can be difficult to describe and have a multifactorial origin.

Data is starting to emerge on broad outcomes after hospital admission for COVID which confirms this. A large UK prospective study has just reported on COVID outcomes 12 weeks after hospital discharge (Arnold et al 2020). 74% of patients had persistent symptoms, especially breathlessness, fatigue, and insomnia, despite a low rate of persisting clinical abnormalities.

This data is in line with the concept of 'long COVID', a complex multifactorial syndrome. These presentations, which can be highly distressing and debilitating, require comprehensive multidisciplinary treatment approaches to provide accurate early management.

The mental health needs of COVID patients are inextricably linked with their physical rehabilitation, so delivery of their mental health care must be well integrated with wider rehabilitation teams.

Current Provision of Post-COVID Mental Health Care

In June 2020, the UK-based COVID Trauma Response Working Group issued guidance that all patients affected by severe COVID should be screened regularly for mental health complications. Leading Scottish ICU consultants felt that this would only be possible with greater dedicated resources available to treat patients adequately in the community.

Currently there are no dedicated mental health services for COVID patients in Scotland. Mental health needs linked to physical illness are often not well met by existing services, as they tend not to reach thresholds for general adult mental health services until they are severe and entrenched. Access to clinical health psychology and allied health professionals is variable, with many services being aligned to and funded by condition specific teams. Many areas have no access to outpatient liaison psychiatry. Some areas have begun to develop mental health referral pathways for COVID, but without protected staffing these are unlikely to be sustainable, especially as regular services restart, and tend not to be joined up with other rehab services.

In many areas of Scotland, community AHPs have rapidly assembled COVID recovery services, often arranged as a single point of access. Mental health services have tended not to be directly involved, although mental health OTs are sometimes included, to good effect. These teams provide excellent support for many patients recovering from COVID. However, these teams tend not to have dedicated funding and are often primarily telephone advice lines.

Community respiratory rehabilitation teams, who may have some psychology input, also provide rehabilitation for some COVID patients, however many patients do not have access to this. This is especially relevant given the recent findings (above) that symptom severity and functional impairment is often far greater than specific clinical findings, so many patients would not have access to these services.

Many COVID patients have particularly complex multifactorial presentations. These patients require comprehensive multidisciplinary services who have developed expertise in dealing with complex presentations, and mental health input into these teams is essential. Scotland has some services with expertise of complex rehabilitation such as cardiac rehabilitation services, but none specifically aligned with COVID.

COVID patients who have required ICU can have additional rehabilitation needs. Post-ICU rehabilitation is an established standard (NICE 2009, FICM 2020), but most Scottish ICUs provide this only partially and with limited mental health involvement. The well-regarded InS:PIRE programme provides follow-up support and psychoeducation delivered in a group setting in some Scottish centres. A limited number of ICUs currently provide personalised care management and direct access to mental health treatment. Eight of 19 Scottish general ICUs currently have no rehabilitation programme.¹

Patient Voices

In any intervention the voices of patients and carers are key in identifying needs, guiding priorities, and ‘telling us what works.’

“On speaking with the mental health clinician, I thought I was ok until the right questions were asked, then I realised I felt at my lowest at that stage. I would never have spoken of my hallucination experience otherwise. I would have held on to these thoughts and pushed them to the back of my mind as I wouldn’t have been able to deal with them. I didn’t understand them. I fear they would have manifested as something else. So when I was given an explanation, I understood for the first time. I understood my experience as normal under the circumstances and not something to be isolated with and secretly fear. I feel very grateful for the service provided and feel things would be worse for me if I the service had not been there.”

¹ Faculty of Intensive Care Medicine Life after Critical Illness audit data, 2020

This patient had been contacted four weeks after discharge from ICU, and was found to have high levels of post-traumatic stress. The patient recovered within two weeks of intervention. The same patient was asked what could have been better:

‘Making sense of it all psychologically at the earliest point would have been certainly better for me. Even in ICU. I was awake and able to have a conversation.’

The voices of patients experiencing long COVID are especially important to hear. Professor Paul Garner discusses his experience of profound persisting fatigue after COVID and identifies the importance of excellent rehabilitation and physiotherapy: <https://blogs.bmj.com/bmj/2020/06/23/paul-garner-covid-19-at-14-weeks-phantom-speed-cameras-unknown-limits-and-harsh-penalties/>.

RECOMMENDATIONS: KEY PRINCIPLES

- * care should be personalised
- * proactive, early engagement and continuity of care
- * early access to expert assessment and treatment
- * integration into multidisciplinary rehabilitation teams
- * joined up rehabilitation structures
- * recovery model approach, emphasising self-efficacy and person-centred care
- * family and carers should be involved at every stage and their needs should also be addressed
- * flexibility and agility to adapt to an evolving pandemic

RECOMMENDATIONS:²

1. COVID Mental Health Lead Clinicians to be established in each locality

A senior, experienced mental health clinician should be immediately appointed as COVID Mental Health Lead Clinician (LC) within each locality. This post should be filled by the most appropriate person in each region, with relevant experience in physical health and expertise across mental health.³

The LC will be the named mental health clinician for COVID patients and personally provide direct clinical care. They will work in acute hospitals and in the community,

² Funding should be linked to measurable outcomes – see Appendix A.

³ In order to rapidly fill these posts, the most appropriate person with relevant experience in each region should be recruited. Funds should be made available to backfill those seconded from other roles. The national implementation lead should be involved in selecting candidates for these posts. This report deliberately does not specify the discipline of these clinicians, but the role should be filled by senior, experienced clinicians, with broad experience of delivering mental health care including acute presentations, and experience working in physical health care environments. It may be that this mix of skills may best be met by more than one individual in some areas. Disciplines well suited for these posts may include liaison psychiatry, clinical health psychology, occupational therapy, and mental health nursing.

embedded in local rehabilitation teams, ideally as part of comprehensive multidisciplinary COVID recovery teams to provide single points of access and combined working.

The LC will proactively and rapidly engage patients. All patients who have been in hospital for COVID should be sent mental health screening tools along with open-ended invitations to contact the service for concerns about their recovery.⁴ The service should also be widely publicised to the public and to other clinicians, who could directly refer into the service.

The LC will deliver early, expert assessment and specialist therapies as required, linking in with existing services where available, or escalating for specialist assessment when necessary. They will have robust links with local mental health services and other specialty services including neuropsychology, vocational rehabilitation, mental health social work, financial inclusion and housing supports, third sector organisations, and peer and carers support services.

They will work in a flexible, agile way. Patients affected by PTSD or cognitive impairment and those with social isolation or deprivation will often have higher rehabilitation needs and have more difficulty engaging with traditional services. Continuity of care is essential, especially as COVID is an evolving condition with potential late manifestations. Formal screening should be repeated over one year. A “no-discharge” policy also supports patient confidence and can paradoxically decrease service utilisation.

The LC will also work with family and carers, both in supporting patients together but also, crucially, addressing carers’ own mental health needs. Caregivers should be explicitly invited to contact the LC and/or should be screened and referred if required.

Additionally, access to local liaison psychiatry is essential, for both inpatients and outpatients, for prescribing and complex diagnosis.

2. Establishment of a National Network for mental health sequelae of COVID

A national network of COVID mental health lead clinicians should be developed. This will allow shared learning, dissemination of new scientific knowledge on COVID, monitoring for evolving clinical features or additional needs, and provide a mechanism for service evaluation to ensure quality of provision across the country.

A National Clinical Lead should be appointed to coordinate the network. National Specialist Advisors, including liaison psychiatry, neuropsychology, psychological trauma, and clinical health psychology, should be centrally funded to link into this network, to provide advice and guidance as well as virtual consultation where necessary. These roles would also develop national professional guidance and patient information resources.

⁴ Screening measures in Appendix B.

3. Multidisciplinary COVID Rehabilitation Teams to be strengthened

Rehabilitation services for COVID patients should be fully joined up and streamlined. From the patient-facing side they should be easy to access via a single point of access. These should be combined-working teams with significant mental health input via the COVID mental health clinicians. Standalone services should be avoided. These teams should have integrated specialist rehabilitation input from services with expertise in complex presentations, for example chronic fatigue services and potentially cardiac rehabilitation services, as well as vocational rehabilitation and cognitive rehabilitation. They should also link in with third sector services who are often well suited to support patients' recoveries especially with long COVID symptoms such as fatigue, and with social services.

These teams require protected time and to deliver direct clinical care rather than be limited to telephone advice.

4. Establishment of Post-ICU Rehabilitation Programmes in all critical care units

The establishment of comprehensive post-ICU rehabilitation teams in the context of COVID could then be maintained beyond the pandemic, in order to meet this need for all Scottish ICU patients requiring complex rehabilitation.

Post-ICU rehabilitation should begin at the point of step-down to general wards and should continue into the community. They should include senior AHP and mental health clinicians to provide early, bespoke rehabilitation. They should provide psychoeducation about delirium and expected emotional responses and personalised lay summaries explaining their ICU stay.

Current programmes should be expanded to work in hospital and over the transition home, and to provide direct mental health treatment, and individual care management. Named recovery coordinators should build relationships with individual patients to reduce anxiety and ensure personalised provision of service.

Benchmarks on the composition of post-ICU rehabilitation teams are provided in the appendix C and are described in NICE and FICM guidelines.

5. National Digital Platform for Patient Information

Access to clear and reliable patient information via a digital platform is essential to the success of clinical care. Patients and their families need to access information relevant to themselves and their stage of recovery, that they can return to as they progress. Reliable digital guided self-management resources are particularly important for patients experiencing long COVID.

The current digital landscape around COVID can be confusing, especially for patients recovering from COVID who may be experiencing severe fatigue, anxiety, concentration or memory problems. Patients and families can be unsure which information to trust, and professionals unsure which to recommend. Additionally, the

development of multiple essentially similar patient information tools is an inefficient use of clinician time.

Scotland needs a national digital information platform for COVID recovery. This could be a standalone resource, or be integrated into an existing site, as long as the user experience is clear, uncluttered, and allows patients to quickly find the information they need for their recovery. It could link to other digital resources for those seeking further information, but the main resource should have sharply curated content.

The resource should meet the following criteria:

- Accurate but succinct content
- Tailored and adaptable to each patient's needs during recovery
- Easy to use
- Able to be delivered quickly

This resource should combine information on physical and mental health aspects of recovery. NHS England has recently launched a "your COVID recovery" website, which is a good example of the type of resource required for the Scottish audience.

Patients who have been in ICU require additional content related to their specific experiences. Targeting is especially important for this group, as the range of procedures and complications is vast and often distressing. Bespoke digital bundles can be specifically tailored to support each patient's correct recovery. This sort of platform can be closely linked to interactions with the healthcare team, including while patients are still in hospital.

6. Peer Support

Peer support is invaluable to recovery from traumatic and isolating experiences like severe COVID. It offers patients and families something that professionals alone cannot, the sense of being truly understood and of shared experience.

The charity ICUsteps explains this well:

"Feeling you're isolated and that no-one understands what you've been through makes it so much harder to come to terms with the trauma of surviving critical illness. This is where support groups can help. Talking to people who've been through similar experiences, who are further down their recovery journey can help you realise that what you feel and think is normal for someone who's been critically ill, and usually gets better.

Simply being able to talk with people who actually understand you because they've been there too can go a long way to help survivors put their experience behind them and get their normal lives back. You may even be able to help other more recent patients as your own recovery progresses."

Peer support should be integrated into post-ICU follow-up services, provided in buddy-ing arrangements to individuals and families, and peer support groups should be extended across Scotland for COVID patients their families and carers.

Peer support groups are already successfully established in some Scottish settings for post-ICU and transplant population. Post-ICU peer groups are particularly well suited to reaching out to COVID patients, as they will share many of the same recovery issues and crucially this will allow support from people further on in their recovery. They already have a well-established infrastructure and culture and will be able to quickly extend to COVID patients. These groups have now become virtual, allowing increased flexibility in the development of new groups, including for example groups for patients and/or families, and to reach across geographic distances.

7. Additional recommendations

Bereaved families support

Losing family members in hospital to COVID can be especially sudden and traumatic, and visiting restrictions have made this even more painful. Complicated grief and even PTSD can result. The Scottish Government should consider increasing support to bereavement charities at this time and should encourage boards to extend bereavement support services in hospital.

Staff support

The value of wellbeing support for healthcare workers has been recognised during the first wave of the pandemic. Effective forms of support, especially wellbeing rooms, facilitated team reflection, and the PRoMIS programme, should continue to be supported.

PROJECTED TIMELINES AND LEGACY OPPORTUNITIES

COVID is a novel illness and the timeline of the pandemic and of its clinical course is difficult to predict. We do know that mental health reactions to physical illness typically manifest over the first year after the illness. Many of these conditions can be treated relatively quickly if treated early. Therefore it could be estimated that the clinical services proposed in this report could be required for approximately two years.

The establishment of well-integrated community-based complex rehabilitation teams with dedicated mental health clinician involvement for COVID could potentially then be maintained for patients with complex community rehabilitation needs who do not fall under current disease-specific rehabilitation teams.

SUMMARY

Scotland has excellent mental health resources. This proposal aims to arrange local experts so they can be accessed by patients recovering from severe COVID and emphasises the need for this to be fully integrated into comprehensive recovery services. It also provides digital resources, peer support, and a national structure to ensure quality delivery, in order to best support our patients to recover physically and mentally from COVID. This robust structure will also allow monitoring and scaling of the service as the pandemic evolves.

These recommendations will also benefit COVID patients who have not been hospitalised. By integrating the mental health leads closely within multidisciplinary teams, learning will spread to all clinicians. New digital resources will also benefit all COVID patients. Non-COVID ICU patients will benefit from expanded post-ICU rehabilitation teams.

This report intentionally recommends a new service. COVID is a new illness and the particular characteristics of its mental health effects, which are complex and emerging, require an agile and flexible response. Named clinicians are the centre of this service in order to provide a truly person-centred response.

By helping to mitigate serious long-term impact of COVID, these recommendations provide an excellent opportunity to ‘invest to save.’ The implementation of a robust nation-wide service would place Scotland at the forefront of efforts to meet this need.

1 October 2020

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These recommendations are fully in line with the Scottish Government’s “Framework for Supporting People through Recovery and Rehabilitation during and after the COVID-19 Pandemic.”

References

Guidance

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NICE clinical guideline 116: Post-Traumatic Stress Disorder, 2018

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Appendices

A: Suggested evaluation and outcome measures:

- Percent of patients engaged
- Percent of patients seen while in hospital
- Percent of high-risk patients engaged
- Patient, family and referrer satisfaction measures
- Screening measures completed at time of engagement and 12 months
- Time from positive screen to clinical assessment
- Time from assessment to initiation of treatment (presence of wait list)
- Percentage of patients completing treatment
- Clinical service extended to family and carers
- Scores on clinical measures plus appropriate quality of life measures (to be developed in coordination with the COVID Trauma Response Working Group)

B: Suggested screening measures:

- HADS (Hospital Anxiety and Depression Scale)
- TSQ (Trauma Screening Questionnaire)
- Cognitive Change Index (subjective cognitive change screen)
- Bespoke measure of positive coping
- Sleep measures

C: Indicative Post-ICU Rehabilitation Team Composition: Benchmarks

Multidisciplinary Post-Critical Care Clinic at Guy's & St Thomas' NHS Foundation Trust:

- Critical Care Consultant
- Critical Care Nurse
- Physiotherapist
- Occupational Therapist
- Psychologist (and referral to Liaison Psychiatry)
- Dietician
- Pharmacist

Recovery and Rehabilitation for Patients Following the Pandemic, Faculty of Intensive Care Medicine Position Statement and Provisional Guidance, May 2020: "The range of healthcare professionals involved in delivering the assessments and interventions:

- ICU nurse
- Clinical psychologist
- Intensive Care Consultant
- Rehabilitation Medicine Consultant (where available)

- Physiotherapist
- Pharmacist
- Social worker
- Dietician
- Admin
- Speech and Language Therapist
- Neuropsychiatrist or Liaison Psychiatrist
- Occupational Therapist



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