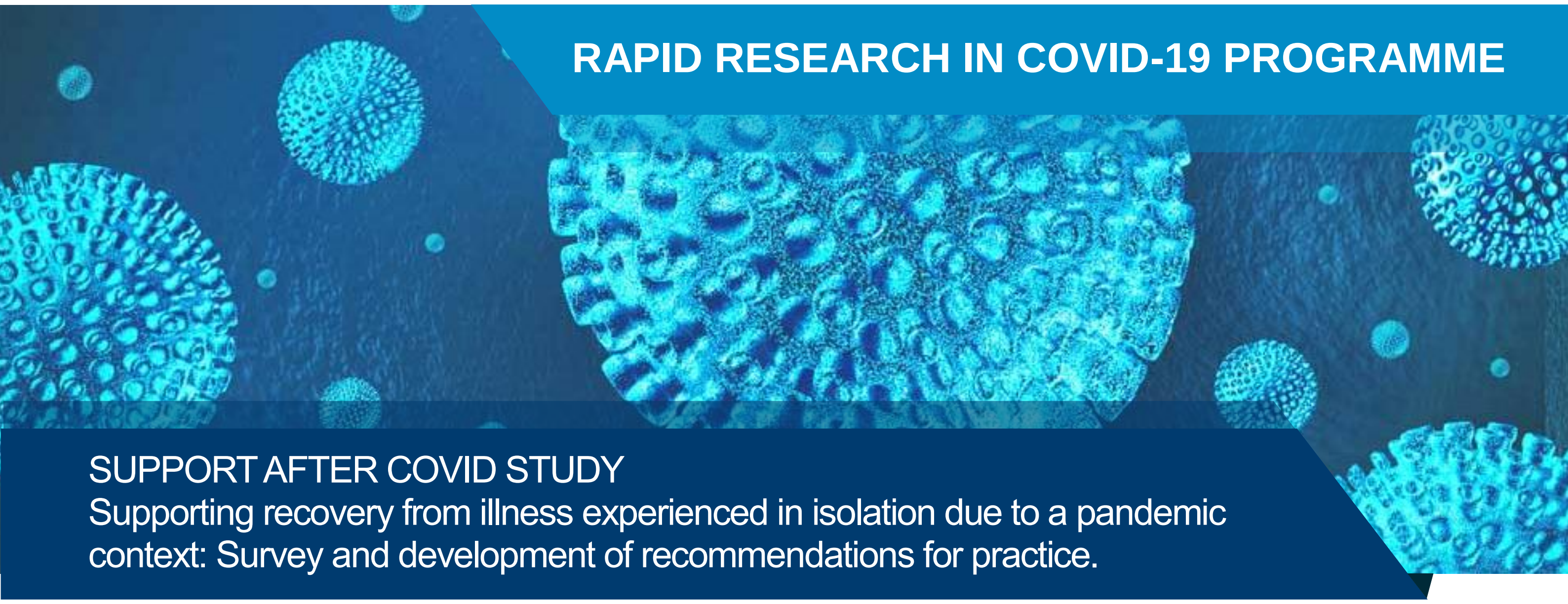

RAPID RESEARCH IN COVID-19 PROGRAMME

SUPPORT AFTER COVID STUDY

Supporting recovery from illness experienced in isolation due to a pandemic context: Survey and development of recommendations for practice.

AIMS

Many people have fallen ill during the pandemic, with COVID-19 and other health conditions, and have felt socially isolated due to the lack of family support possible at home or in hospital.

This study aimed to find out more about people’s experiences of:

- feeling socially isolated when experiencing COVID-19 or other illnesses or health conditions;
- what support people might need during their recovery; and
- what factors stakeholders think will affect access to this support.

We aimed to use these insights to make recommendations for the support that is likely to be needed, and how to make such support accessible.

KEY FINDINGS

Our study produced eighteen recommendations, detailed in the appendix, that aim to enhance the care experience of people who have been unwell during the pandemic. These are summarised within four principles briefly outlined below:

- Support should be person-centred and needs-led, with a more holistic approach to supporting people in their recovery and return to life roles and activities wherever possible.
- Policy should be coordinated across sectors to ensure clear messaging and avoid confusion.
- Information should be reliable, trusted, up-to-date, evidence-based and easily accessible to people with different abilities and resources.
- Access to support should be equitable and not affected by personal, population or lifestyle characteristics of the individual.

WHAT DID THE STUDY INVOLVE?

This was a rapid and multi-faceted research study. The first stage explored people's experiences of illness and isolation using an online survey. All respondents were asked about specific demographic characteristics, whether they felt isolated and their experience of illness, including COVID-19, during the pandemic. They were also asked to complete validated questionnaires on post-traumatic stress symptoms[1], and about experiences of loneliness[2]. Responses were analysed and recommendations for meeting the support needs of participants were developed. We did not make any arrangements for distributing the survey through other means due to restrictions at that time in the pandemic.

Following development of recommendations, a second online survey was promoted through social media (@SupportAfterCovidStudy) asking participants to comment on how appropriate they thought the recommendations were and whether anything was missing. People were also asked about what they thought it would be like trying to access the support mentioned in each recommendation. We also discussed these questions through focus groups and interviews with eight people who had ongoing effects of COVID: 'Long-COVID' (members of www.longcovid.org) and an advocate for people living on low incomes. Finally, we held tweetchats to discuss these issues with service providers, including nursing and allied health professionals[3,4]. We thematically analysed the qualitative data. Our study was reviewed by Queen Margaret University Ethics Committee.

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

We had 675 complete responses to our online survey. Using statistical analysis of questionnaire scores, we found that people who have been, or have felt isolated (495 people) are at risk of post-traumatic stress, as are people who have experienced health conditions or illness during this period (299 people). We found substantial support needs were described by people who had experienced COVID-19 (45 people) or were still experiencing COVID-19 (85 people). This included fatigue, breathlessness, problems with mobility and difficulty completing home care tasks. People had very diverse symptoms that suggested different parts of the body had been affected.

Respondents who were unwell with illnesses other than COVID-19 (such as chronic fatigue syndrome, asthma, rheumatoid arthritis) were most likely to experience mental health difficulties, including anxiety and depression-related symptoms and struggled to access health and social care support services.

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[1] Weathers, F.W., Litz, B.T., Keane, T.M., Palmieri, P.A., Marx, B.P. and Schnurr 2013 http://www.ptsd.va.gov

[2] De Jong Gierveld, J. and Van Tilburg, T. 2010 https://doi.org/10.1007/s10433-010-0144-6

[3] http://wecommunities.org/tweet-chat/chat-details/5589

[4] https://physiotalk.co.uk/2020/09/support-after-covid-physiotalk-mon-5th-october

People who had experienced / were still experiencing impacts of COVID-19 often described feelings of abandonment, fear and confusion. They often felt that health professionals did not understand or recognise their experiences and felt that they had to be highly proactive in seeking help. People found it difficult to attend multiple appointments in different places, which was hard during lockdown and when feeling ill. Limited support and conflicting advice contributed additional stress and anxiety but people were afraid of mentioning this to health professionals as they thought it would undermine their credibility when describing other symptoms.

Our analysis of support needs informed the development of fifteen draft recommendations that focused on guiding health and social care response to support people who have been unwell during the COVID-19 pandemic.

In the second stage of the study we refined and added to the recommendations by working with different stakeholders. We had 43 people complete our online survey, 87 active participants in our two tweetchats, eight people in our two focus groups, and one additional interview.

The results supported refining and retaining all our recommendations and adding three further recommendations (see Appendix). Key findings are listed below:

- When discussing access to support, people were concerned about availability, especially if COVID-19 cases started to rise again.
- There was concern about the development of expertise amongst health and social care professionals and this being dispersed rather than concentrated in one clinic.
- Participants thought that professionals could learn from research into chronic fatigue services.
- People discussed complex barriers to accessing services that relate to specific referral criteria (e.g. relating to age or condition) and lack of continuity between, for example, acute and non-acute health services.
- Participants wanted professionals to share knowledge and good practice rapidly and widely to ensure patients receive good advice, effective symptom relief, and support to resume work or other life roles.
- There were concerns about the increasing use of digital health solutions when there are people who will not have the capabilities or resources to use these.
- People also discussed the challenges of trusting health messages and information when more recently there have been misinformation and conflicting messages, and over a longer time period there have been growing anti-expert attitudes in society.
- There was some consensus that people need different amounts and complexity of support, and services should be designed to incorporate this in relation to crisis care, rehabilitation and recovery, management of ongoing health conditions, and returning to work and previous life roles.
- All stakeholders agreed that all research, information, resources, services and policies should be co-produced with people who have lived experience of COVID-19, Long-COVID, and other health conditions.

We have designed this study with a follow-up stage and it will be important to explore how people's experiences of post-traumatic stress symptoms and of seeking support change over time. Further research is needed to explore people's lived experiences of COVID-19 and of accessing support. It is important that this research carefully considers people who may have fewer personal or financial resources, and who may be under-represented in research; methods designed to enable inclusion are needed.

WHAT IMPACT COULD THE FINDINGS HAVE?

People who have or who have had COVID-19 have support needs, as do people who have had other health challenges when isolated. We intend to achieve impact for people, policy, and practice:

People must be able to trust that they will be able to access understanding and support through their local health services, that they have access to trustworthy information through online support, and that they can talk to someone through a trusted telephone helpline to enable them to find the support they need. People must be able to access the appropriate professional support to enable them to return to their normal life roles where possible, or to find different ways forward where they cannot continue with previous life roles. People with negative impacts from stress, isolation and grief must be able to access support from mental health services. People with negative impacts on their function and fitness due to lack of support for existing conditions, shielding, and working from home must be supported to be as well and able as possible.

Policy development must reflect the complex and interacting issues that affect people's abilities to recover from this pandemic. Communication is needed between sectors such as health and social care, the third sector, workplace and employment; careful consideration of how policies intersect is important to support recovery.

Practice must consider that trust has been eroded in relation to health-related messages and people have feelings of abandonment which impact negatively on their mental health. It is crucial to seek ways to regain credibility and clarity. People are having very different experiences of seeking help and access to support depending on their income, type of employment, culture, experience of existing health conditions, and journeys relating to COVID-19. Any services must carefully consider barriers to access in their design and work to ensure that they do not inadvertently exacerbate health inequalities.

HOW WILL THE OUTCOMES BE DISSEMINATED?

We will be communicating our results and recommendations with policy makers, health and social care service providers, and people whose health has been affected by COVID-19, or associated lockdown measures. Our study has an established social media presence which will enable rapid dissemination through our web page (https://www.cpcpr.org/covid-19-2) and Twitter handle @SupportAfterCovidStudy. We will produce a joint Press release with the CSO and a policy briefing which we will send to appropriate people in the Scottish Parliament and Scottish Government. We will communicate our results in peer-reviewed publications and in conference presentations and will ensure that people in education integrate our findings in relevant professional programmes.

CONCLUSION

Our pragmatic study provides early insights into the effects of the COVID-19 pandemic on people and their resulting support needs. We explored the experiences of people who have been unwell and/or isolated during the pandemic using online surveys interview and focus groups and found that both can lead to post-traumatic stress. We also explored the needs of people who have had COVID-19 and who have ongoing effects: ‘Long-COVID.’ We have developed recommendations for policy and service provision to support people recovering from COVID-19, experiencing Long-COVID, and people who have other illnesses and health conditions who may be unable to access the health and social care services they need. We are carrying out a follow-up survey and qualitative telephone interviews with participants from the first survey to find out more about their experiences of seeking support and about what has helped them most. It is clear that progress is already being made in relation to several of the recommendations, and it will be valuable to find out where further work is needed, to facilitate prioritisation of further development.

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ADDITIONAL INFORMATION

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Appendix: Revised recommendations for supporting people after COVID-19 and people experiencing negative impacts of the pandemic

1. The longer-term experiences of people who have had COVID-19 should be recognised and recorded internationally.
2. Receiving diagnosis and treatment of longer-term conditions relating to COVID-19 should be equal for everyone and evaluated based on patient history and clinical evaluation.
3. There should be national evidence-based guidelines to help develop coordinated policy and services across sectors that improve the experiences of people experiencing COVID-19 and its long-term impacts.
4. There should be national guidelines and education for employers to help people return to all workplaces in a way that supports their recovery.
5. There should be a central, interactive online resource that helps people find current and appropriate support at the time when they need it, developed together with people who have experienced COVID-19.
6. Where people need more support or find it hard to use online resources, they should be able to talk to someone on a trusted telephone helpline about how to find health-related, financial, community, and/or social support.
7. People need person-centred, needs-led support from their local health-services where they are referred quickly for investigations, and specialist support relating to physical and/or mental health needs, ideally through COVID-19 Clinics.
8. According to assessed need, people recovering from COVID-19 should have help with self-care, caring for others, and domestic tasks, including decontamination of the self-isolation space.
9. People should be able to access specialist therapy services that can help them cope with the impacts of COVID-19 on their mental health.
10. People should be able to access needs-led support for recovery from professionals with appropriate expertise to help them with the impacts of COVID-19, and help them safely increase their activities.
11. People should have support from appropriately trained exercise and health promotion professionals to help them safely increase their physical activity and exercise after COVID-19.
12. There should be support for the development and ongoing provision of a network of local and national support groups for people who are recovering from COVID-19.
13. People who are recovering from COVID-19 should be individually assessed for inclusion in the list of people who need to shield.
14. Professionals who work with people who have had COVID-19 should be educated about their experiences, needs, strategies and interventions, and influences on access to support.
15. Researchers should work meaningfully with people of all ages who have had COVID-19 to explore diverse short-term and long-term experiences of COVID-19 and how to provide effective and accessible support.

16 **Appropriate support should be made available to professionals who are caring for people with COVID-19.**

17 **Services that aim to support public health and reduce risk of injury should be strengthened to reduce the risks from isolation, stress, grief and working at home.**

18 **Existing services should ensure that people know how to safely access appropriate support for developing, long-term or degenerating conditions.**