

Royal College of General Practitioners – Written evidence (COV0051)

Ongoing or persistent symptoms of Covid-19 (Long Covid)

The Royal College of General Practitioners (RCGP) welcomes the opportunity to share its response to this important inquiry on the ongoing health impact of Covid-19, currently called 'Long Covid-19'. The RCGP represents over 54,000 General Practitioners across the UK. For the purposes of this document and until a formal definition is determined, ongoing/persistent symptoms of Covid-19 will be used rather than "Long Covid."

1. Summary of recommendations

- All patients who have ongoing symptoms of Covid-19 lasting longer than anticipated should be included in the disease definition, ensuring every patient who has been clinically diagnosed has equitable access to investigation and treatment. This includes patients who have been diagnosed retrospectively and is irrespective of whether patients were hospitalised or not.
- Increased and long term funding must urgently be provided to improve community of access to investigations for ongoing symptoms of Covid-19, such as blood tests, ECG (static and ambulatory), echocardiography, tilt table, chest X-ray, pulmonary function tests, CT and MRI scanning (see Figure 1).
- Increased investment in primary care services must be taken into account, as services are designed to investigate and treat patients with ongoing symptoms of Covid-19. Most patients will be cared for within the community and it is essential that consideration is given to the increased time and resources this new disease will require.
- Increased investment in community mental health services is needed to enable patients experiencing the psychiatric and psychological impacts of Covid-19 to be able to access treatment in a timely fashion. In England, NHS England should to bring forward planned changes to the GP contract to enable primary care networks (PCNs) to direct employ mental health practitioners now, rather than waiting until April 2021.
- Evidence based support for patients is needed to manage all patients with ongoing Covid-19 symptoms. The design and implementation of services should be based upon the final guidance from NICE/SIGN and the RCGP (NICE & SIGN, 2020) , estimated to be published in November 2020, to ensure the correct service is commissioned based on the best evidence base available. The current risk is that these services could be commissioned out of alignment with the national guidance. While interim or pilot measures may need to be put in place to support patients, plans will need to be adapted and finalised only once the NICE/SIGN guidance is completed, and plans should be put in place for evaluation of services.
- Funding must be allocated to enable the Royal Colleges or other appropriate bodies to produce high quality professional educational material to explain the diagnosis, (what it is and what it isn't), the

investigations and treatment available and the impact of this new emerging disease.

- Funding must also be allocated to enable the Royal Colleges or other appropriate bodies to produce high quality, and patient facing resources to explain the diagnosis (what it is and what it isn't), the impact, investigations and treatment for this new emerging disease.
- Increased and long term investment in access to therapies, based in the community, such as physiotherapy, occupational therapy and specialist rehabilitation needs to be secured.
- Commissioning of the Professional Records Standard Board (PRSB) to develop a clinical code alongside NHS digital, to enable accurate recording of ongoing/persistent Covid-19 symptoms in electronic patient records for the purpose of clinical care and to enable further research.
- Occupational health services for primary care health care professionals who are suffering from continuing symptoms of Covid-19 should parallel with those available in secondary care, and we call for a nationally funded primary care occupational health service. These services are required to ensure health care professionals are supported back to work and can continue to care for all patients.

2. Background

Throughout the pandemic, GPs have been working hard to deal with the direct and indirect impacts of Covid-19, including the growing emergence of patients presenting to general practice with persisting symptoms after the initial, acute infection with Covid-19 has resolved. General practice is the first point of contact in the NHS for people who have ongoing Covid-19 symptoms and has a key perspective on this newly emerging condition.

The RCGP successfully led the call for NHS England to commission a National Institute for Health and Care Excellence (NICE) guideline on the long-term effects of Covid-19 (NICE & SIGN, 2020). We have been instrumental in bringing together a multi-professional group from across the UK; and, by collaborating with both NICE and the Scottish Intercollegiate Guideline Network (SIGN), have realised our aim for a single UK-wide national guideline to be published by the end of the year.

Alongside national guidance in this area, more resources are needed to successfully manage patients with persisting symptoms following an acute infection with Covid-19. Much of the resource and infrastructure for Covid-19 has been based on managing the acute care of patients during the early stages of the pandemic. Now is the time to act to ensure the long term management of those with ongoing symptoms matches that of the acute phase of the illness. We must also remember that there are many patients being cared for within primary care with other complex, multisystem disorders, such as chronic fatigue syndrome, who also require equitable access to multi-professional clinics – these patients must not be forgotten.

Finally, it is important to realise that, as knowledge changes with increasing evidence from research into the longer effects of Covid-19, support and treatment systems will also need to adapt.

3. What is 'Long Covid'?

- Long Covid-19 is a name given by patients to the ongoing/persistent condition(s) following an acute infection of Covid-19 that has lasted longer than expected. It is a patient determined definition.
- The cause of ongoing symptoms is currently not certain, but there is evidence to suggest it may be associated with a powerful inflammatory/immune reaction to the initial Covid-19 infection, involving vasculitis/swelling of the inner lining of the blood vessels (Tay,, Poh, Renia, & et al, 2020) (Libby & Luscher, T, 2020).
- The formal definition of persisting/ongoing symptoms will be determined by work being undertaken by NICE and SIGN (NICE & SIGN, 2020) in collaboration with the RCGP, due to be published in November 2020.
- There is no diagnostic test for clinicians to make a definitive diagnosis of persisting Covid-19. The diagnosis is currently considered when a patient presents with a history consistent with Covid-19 infection and has ongoing intermittent or persistent symptoms that were not present before their Covid-19 diagnosis, with a prolonged recovery time.
- It is not necessary to have a positive SARS-CoV2 test to be diagnosed with persistent Covid-19. People may not have a positive test for a number of reasons, including the lack of mass community testing in the first phase of the pandemic, issues with access to testing in later stages of the pandemic in some areas of the country, and because testing for Covid-19 is not 100% accurate with false negative results relatively common (Watson, Whiting , & Brush, 2020).
- Most people will recover from Covid-19 within a short period of time, with an estimated 90% completely recovered within 3 weeks (Greenhalgh, Knight, Buxton, & Husain, 2020). It is currently estimated by some academics that approximately 98-99% recover by 12 weeks, but that significant numbers continue to have ongoing symptoms after 12 weeks. The data beyond 12 weeks is yet to be fully determined and funding must be allocated to secure high quality prospective research in this area to inform future care. The actual figures may be much higher once prospective research data becomes available.
- It is important to note that the figures presented currently may be underestimated due to the natural self-reporting bias in the Covid symptom study app and the potential bias in health seeking behaviour towards those in higher socioeconomic groups, which is evidenced by data from the UCLH clinic (unpublished).
- The ongoing effects of Covid-19 seen in the community presents as a multisystem disease that follows an infection with the SARS-CoV-2 virus. Symptoms described during a survey of GPs in October 2020 include (RCGP, 2020):

- **Fatigue.** General and post exertional fatigue (93%) on minimal exertion.
- **Respiratory symptoms.** Including ongoing shortness of breath (81%) and persistent cough (62%) in addition to ongoing/intermittent low blood oxygen levels.
- **Cardiovascular symptoms.** Including palpitations and irregular heart patterns (42%) blood pressure changes and Postural Tachycardia syndrome (PoTs) in 25%. More serious heart changes have been reported on MRI scanning in 78% of individuals in some studies (Yancy & Fonarow, 2020) and conditions such as myocarditis and cardiac chest pain have also been reported.
- **Neurological symptoms.** Including headaches (55%), neurocognitive disorder such as brain fog, confusion and thought disorder (46%) and dizziness (92%).
- **Musculoskeletal symptoms.** (72%) Including pain and muscle fatigue.
- **Psychiatric symptoms.** (76%) Including sleep disorder and mood changes. It is important to note that mood disorders can be primary, or secondary to the long term effects of the disease and the feeling that it will “never end”.
- **Metabolic disruption.** (20%) Including worsening diabetic control or worsening of underlying metabolic disease.
- **Gastrointestinal upset.** (41%) including nausea, bowel changes and indigestion.
- **General symptoms.** Persistent fever (38%), pain including non-specific chest pain (60%) rashes (20%) and ongoing loss of smell/taste (54%).
- **Thromboembolic disease** (20%) including blood clots in the legs and lungs and stroke.

4. Community diagnosis of ongoing symptoms of Covid-19

From a GP perspective, there are three types of patient we have identified who may have ongoing symptoms of Covid-19:

a) Initial infection not reported to health services and clinically diagnosed retrospectively

- These patients did not contact health services when they initially experienced symptoms, or were referred for self-care via the NHS 111 online tool.

b) Initial Covid-19 infection clinically diagnosed

- *Clinically diagnosed in the community.* These patients have no Sars-CoV2 test due to lack of community testing in phase 1 of the pandemic and ongoing restricted access to testing.
- *Clinically diagnosed in hospital.* These patients may have presented to A&E at a time when testing was only completed for patients *admitted* to hospital in the first wave of the pandemic, or if patients presented to hospital towards the end of their acute phase of illness (e.g. day 8-10 which is a common deterioration time) when testing may have been negative, as SARS-CoV2 testing is most accurate in the first 5 days (Watson, Whiting , & Brush, 2020).

c) Initial infection diagnosed with positive Sars-CoV2 test

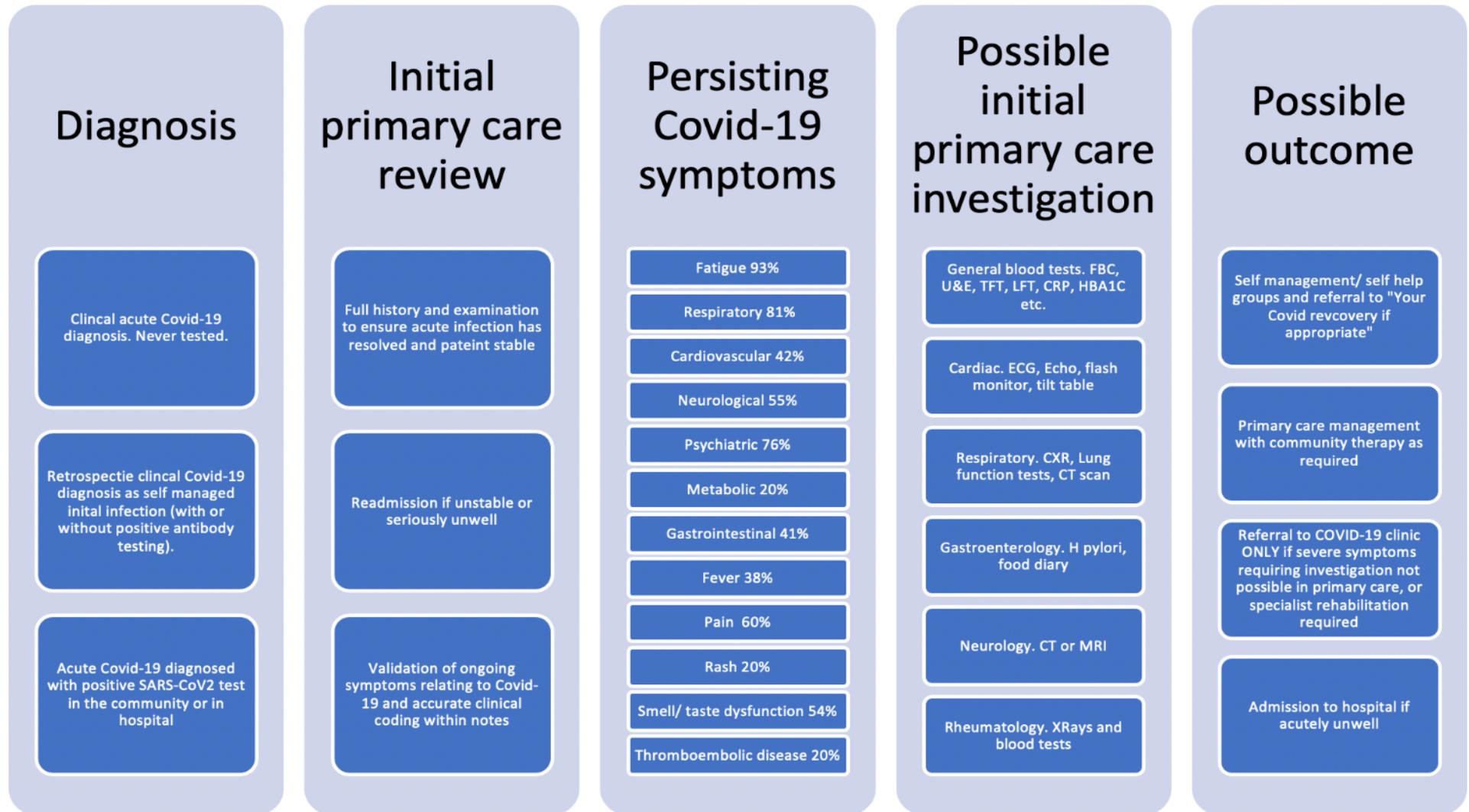
- These patients have a positive SARS-CoV2 test, either from a hospital or community.

It is important to note that there is also a distinct group of patients who have end organ damage as a result of their acute Covid-19 infection. For example, having stroke due to thromboembolic disease or renal failure following an ITU stay. This group of patients must be considered separately as having "sequelae" of Covid-19 (health consequences of a complication of Covid-19) rather than having 'Long Covid-19'.

5. Managing ongoing or persistent Covid-19 in primary care (see Figure 1)

- The multisystem nature of the long term effects of Covid-19 is best served by generalist management in primary care in the first instance. This will enable patients with ongoing Covid-19 symptoms to have holistic, relationship-based care that considers the physiological, psychological and social impacts of their condition. Patients and their GPs work together to make decisions about care is best for them, according to their needs and preferences. This will also prevent the need for multiple referrals (e.g. cardiology, respiratory, neurology and rehabilitation), with onward referral only needed if specialist intervention is required.
- The optimal management of persistent Covid-19 is dependent on the severity of ongoing symptoms:
 - Patients with **mild ongoing** symptoms can be self-managed in the community. These patients may contact their **GP for support**, sick certification and reassurance.
 - Patients with **moderate ongoing** symptoms will require **GP led care and possible investigation**. It is essential that symptoms are investigated fully to ensure serious or life threatening diagnoses such as an underlying cancer are not missed.
 - **Severe ongoing** symptoms will require **initial generalist-led care and investigation followed by specialist intervention** when appropriate, such as onward referral to multidisciplinary rehabilitation teams or specialist services such as cardiology or respiratory physicians.
 - **Patients with Covid-19 sequelae** have ongoing symptoms due to the long term effects of end organ damage (e.g. stroke due to thromboembolic complications of Covid-19) and will initially require secondary care intervention but long term, will require **GP-led management of the resulting long term chronic disease**.

Figure 1: The patient journey for ongoing or persistent symptoms (RCGP, 2020) of Covid-19 in Primary Care. Initial Covid-19 infection must have resolved. Average infection length 10 days, with an estimated 90% recovered by 3 weeks (Greenhalgh, Knight, Buxton, & Husain, 2020)



6. Experience of ongoing Covid-19 in primary care

- With an estimate of at least 60,000 people in the UK with ongoing effects of Covid-19 (Greenhalgh, Knight, Buxton, & Husain, 2020), which may be an underestimate due to reporting bias and lack of longitudinal population studies, there continues to be a significant impact on the workload within primary care. Patients with ongoing symptoms require a full history and examination to be undertaken, may need baseline tests to be performed, sick certification to be completed and continued reassurance and support. In addition, ongoing management of long term conditions, and sequelae of Covid-19 disease such as stroke or renal disease, and onward referral to specialist services may be required. Once specialist services discharge these patients, they will then again be under the long term care of their General Practitioner.
- The total increase in the contact time required within general practice cannot yet be fully determined due to the new emerging patterns of this disease. It is, however, essential that the impact on an already overstretched primary care workforce is taken into account when funding is allocated for the ongoing care of those with persisting Covid-19 symptoms.
- Access to investigations is varied throughout the UK. Only 7% of GPs surveyed by the RCGP (RCGP, 2020) felt that they had good access to the diagnostic tests they need to investigate the ongoing symptoms relating to Covid-19 in the community. An astounding 50% not having any community access to these tests at all. It is essential investment is made immediately to enable primary care clinicians to have better access to these tests as shown in Figure 1.
- We welcome the announcement on 1 October 2020 regarding NHS England diagnostic hubs, including essential tests for cardiac and respiratory disease relating to Covid-19 (NHSE, 2020). We would like to see these hubs, or availability of these diagnostic tests, to be made urgently for GPs to access to care for their patients with ongoing Covid-19 symptoms.
- It is important to recognise that this disease is not yet accepted across the whole of the NHS. Initial reports from patients showed a lack of knowledge and understanding of clinicians in both primary and secondary care. The RCGP listened to these patients concerns and is actively working to ensure its 54,000 members have access to high quality educational resources including online e-learning, top tips for GPs and a webinar. However, centralised funding should be allocated to provide high quality information for health care professionals, across primary and secondary care based on the national NICE/SIGN/RCGP guidance to enable rapid access for clinicians upon publication. This will enable them to understand and accept this new diagnosis, and know how best to investigate and treat it.
- The patient must always be kept at the centre of their own health care needs. It is therefore vital that they understand the ongoing symptoms that they are experiencing and what investigation and treatment is available for them. Relationship-based care in general practice will fill some of this gap but it is important that central funding is allocated to develop high quality patient facing resources to understand this new diagnosis, what investigations are required and how best to treat it.
- The RCGP recognises the criticism aimed at both primary and secondary care professionals who have not fully understood the impact of the longer

term symptoms associated with Covid-19 as new evidence of the disease emerges. Whilst many clinicians are providing excellent care, some require additional help with 81% of GPs surveyed calling for national guidance to help them (RCGP, 2020). Whilst patients have reported lack of care from their GP, GPs have also reported difficulty accessing care from secondary care demonstrating that this is a whole system problem.

- Access to specialist clinics for ongoing Covid-19 symptoms is variable across the country with only 23% of GPs surveyed (RCGP, 2020) having access to a 'Long Covid clinic' that they can refer into. Significantly, approximately a fifth of those GPs surveyed said some patients had been prevented from being referred because they did not have a positive SARS-CoV-2 test. The announcement on 7 October 2020 by NHS England of their investment in 'Long Covid clinics', which will include both specialists and generalists such as GPs, is welcomed (NHSE, 2020). However, it is essential that similar services are available to all patients, irrespective of whether they were admitted to hospital or received a positive SARS-CoV2 test, are able to access them through referral from primary care.
- Not all patients with ongoing symptoms will, however, require referral to a specialist 'Long Covid clinic'. Many simple tests (as outlined in Figure 1), especially in the early course of the disease, can be carried out by GPs that enable the ruling out of serious complications of Covid-19. These tests are also able to rule out the need for onward referral and identify separate, undiagnosed diseases (such as a malignancy) that may have masqueraded as a symptom of ongoing Covid-19. Investment must be put in place to increase community access to tests that will be required.
- The RCGP requests that the "Long Covid clinics" and "Your Covid recovery" announced by NHSE (NHSE, 2020) align with the evidence-based national guidance commissioned by NHSE (NICE & SIGN, 2020), which will be published in November 2020. The final design and implementation of these clinics should be based upon the national guidance from NICE/SIGN/RCGP to ensure the correct services are commissioned, based on the best evidence available. The current risk is that these services could be commissioned out of alignment with the national guidance due to time pressures, although investment may be better used in other ways. While interim or pilot measures may need to be urgently put in place to support patients, plans will need to be adapted and finalised only once the NICE/SIGN guidance is completed. Plans should also be put in place for evaluation of these services.
- 76% of GPs surveyed by RCGP (RCGP, 2020) have described patients with psychiatric complications of Covid-19, such as sleep disorder and mood changes, either as a primary change or as a result of increasing frustration of the length and course of the disease. Whilst GPs support their patients emotionally, investment in mental health, psychology and counselling services to ensure rapid access to specialist care in the community is needed. This could in part be achieved in England, by bringing forward funding allocated to PCNs, currently scheduled for 2021, to employ mental health practitioners immediately at a local level to support our patients. This should sit alongside investment into wider community mental health services.

- Currently, there is no code available to record ongoing/persistent Covid-19 symptoms in electronic patient records. In April 2020, the Professional Records Standard Board (PRSB) worked closely with NHS Digital to rapidly convene professionals and patients to define codes for recording of acute Covid-19 related information. Currently, the RCGP is working closely with the PRSB and NHS Digital and has highlighted the need for commissioning of this service to NHSE. Investment in the coding process and formal commissioning of the PRSB to define these codes is essential to maintain the coding standards for all Covid-19 infections, enabling better clinical record keeping, informing ongoing patient care, and facilitating research.

Support for the profession affected by ongoing symptoms of Covid-19

In addition to supporting the population, there must be more focused support for GPs and their teams. Many health care workers in primary care contracted Covid-19 while caring for patients in the first wave and some are experiencing prolonged Covid-19 symptoms resulting in long-term sickness absence. This increases pressure on the primary care teams continuing to deliver services. Occupational health provision is readily available in secondary care, as hospitals are large organisations. GPs work in small businesses that are contracted to provide NHS services, with no centrally provided occupational health support. The RCGP would like to see provision of services, such as funded occupational health and funding for suitable staff cover, in place to ensure health care professionals are supported back to work and to continue to care for all patients.

7. Future research

The long term effects of Covid-19 beyond 6 months are currently unknown, due to the nature of a new disease, and this is an important area for investment in research. Sufficient funding must be allocated to complete this work in a timely fashion, and to enable longitudinal research that is conducted over a significant period of time to capture a true picture of the disease and its impact. Research must be across primary and secondary care and include prospective data collection. Areas to consider include:

- **The disease itself.** The clinical nature, progression and prevalence of the condition must be prospectively explored in both primary and secondary care settings. This will allow the course of the disease to be fully explained and improve diagnostics aiming to predict the development, progression and long term impacts of this condition. We do not yet know how long the persistent symptoms will last and so it is essential that any long term research is funded for an adequate length of time and as a minimum for 5 years. This must cover the demographic and biopsychosocial aspects of the disease.
- **The impact of persisting Covid-19 on other comorbidities.** We know that Covid-19 can be more severe in people with diabetes. We need to understand which comorbidities exacerbate long term Covid-19, and if this ongoing or persistent Covid-19 effects long term conditions patients are already living with.
- **The impact of ethnicity on persistent Covid-19.** We know that currently Covid-19 affects those from a BAME population disproportionately. Research

is required to determine if this transfers to long term impacts of the disease across populations.

- **The impact of deprivation.** It is essential that comparisons are made to determine what, if any, impact deprivation has on the long term effects of Covid-19.
- **Service delivery.** The impact of new services to investigate and treat the ongoing symptoms of Covid-19 must be researched. This should compare intervention at all stages of the patient journey including self-help, GP-led care and specialist intervention to determine the long term best place for these patients to be managed.
- **Impact on the NHS and services across primary and secondary care.** Prospective research to determine the impact of persisting Covid-19 on the delivery of NHS services, the workforce and any impact on standard NHS care.

It is essential that government and healthcare leaders act now to ensure that there are the resources are used to build the necessary infrastructure to address the needs of long term Covid-19 patients. This must take place alongside the development of the guideline on persisting symptoms of COVID-19. The system must be ready to respond quickly, and clinicians across primary and secondary care must to be supported to care for the needs of patients at this time.

The long term effects of the virus should be taken as seriously as those in the acute phase of the illness, and our response to the long term management of those with ongoing Covid-19 symptoms should match that of the acute phase. Now is the time to act to ensure that people receive the care they need.

15 October 2020

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