Royal College of General Practitioners

# Management of the long term effects of COVID-19

## The RCGP response and top tips for caring for our patients.

V1 30th October 2020.

This will be updated once the national guideline has been produced by NICE/SIGN and the RCGP in December 2020

## Background

A survey of RCGP members in September 2020 showed 67% of those who responded were looking after at least one patient with ongoing symptoms of COVID-19 lasting more than 12 weeks. Realising the impact of this new disease on general practice and with 81% of respondents asking for more clinical guidance to help look after these patients, on behalf of our members, we lobbied for funding of a national guideline.

Whilst NICE were being commissioned to produce this guidance, RCGP clinical policy team became aware that SIGN were also beginning to review the evidence base. To prevent 2 potentially conflicting guidelines being produced at the same time, we asked both SIGN and NICE to collaborate with us, to create a single UK wide guideline which was approved and announced on 5th October 2020. It has been acknowledged in the scope of the guidance that we are only at the beginning of understanding the ongoing effects of COVID-19 and that there is still much uncertainty surrounding it. For that reason, the NICE/SIGN/RCGP guidance will be classed as a "living guideline", meaning it will be continually reviewed and updated in response to changing and emerging evidence.

At present, there is no completely accurate indication as to how many people are experiencing persisting ill health following COVID-19. Current estimates are based on extrapolated figures, or from self-reporting of symptoms in an ap, and whilst this can give us an indication of the number, until we have a cross sectional population study, the true prevalence cannot be fully known. To aid the collection of data and to inform prevalence, the RCGP clinical policy team has also worked closely with NHS Digital and the Professional Record Standards Body (PRSB) to ensure codes will be available for us to use (in both primary and secondary care), which will help us care for our patients and inform the population based data needed to further shape the services required to fully assess and treat this disease.

The definition and scope of the NICE/SIGN/RCGP guideline is published today (30th October) and we have summarised this for you below. We've also included some top tips to aid the care of your patients whilst waiting for the national guidance to be produced.

## Definition of the disease for the purpose of the guidance


Post covid-19 syndrome is defined as "Signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body". It is, however, important to know that "post-COVID-19 syndrome may (also) be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed".

## Top tips for caring for patients whilst waiting for the NICE/SIGN/RCGP guidance

### 1. Post COVID-19 syndrome is a real condition

*Believe your patient, listen, show empathy and acknowledge the diagnosis.*

"Finding the right GP" : A qualitative study of the experiences of people with Long covid, shows the importance patients with ongoing symptoms of COVID-19 placed on being believed by their GP and shown empathy and understanding. Data from the RCGP survey of members concurs with this, showing that 73% of those who responded believed that listening and empathy were beneficial for their patients suffering with ongoing symptoms of COVID-19.

2. **You do not need a positive SARS-CoV-2 test, or have been admitted to hospital to be diagnosed with post COVID-19 syndrome**

*Anyone with an acute infection of COVID-19, however mild, can go on to develop post COVID-19 syndrome.*

Since mass community testing was not available in the first wave of the pandemic and the knowledge of the potential of false negative results even when testing is available, it is important, as highlighted in the RCGP House of Lords report, that we consider a diagnosis of post covid syndrome in *all* patients with ongoing symptoms, irrespective of whether they had a positive test in their acute COVID-19 illness . This includes those who are:

- Self-diagnosed with COVID-19 based on the clinical criteria and self-cared in the community during their acute illness
- Clinically diagnosed with COVID-19 by a health care professional including 111/NHS24, primary and secondary care, with or without testing
- Diagnosed with SARS-CoV-2 testing in the community or in hospital

3. **Post COVID-19 syndrome is a multisystem disease**

*Do not dismiss ongoing COVID-19 symptoms as anxiety or due to psychological cause. A full history and appropriate examination is needed to understand the impact of COVID-19 on your patient*

The NICE/SIGN/RCGP definition is clear that post COVID-19 "can affect any system in the body" with the RCGP survey showing that in the community, the most common symptoms/systems affected after 12 weeks were:

- **Fatigue** General and post exertional fatigue in 93%, on minimal exertion.
- **Respiratory symptoms** Including ongoing shortness of breath in 81% and persistent cough in 62%
- **Musculoskeletal symptoms** in 72% including pain and muscle fatigue.
- **Neurological symptoms** Including headaches in 55%, neurocognitive disorder such as brain fog, confusion and thought disorder in 46% and dizziness in 52%.
- **Cardiovascular symptoms** Including palpitations and irregular heart patterns in 42% and Postural Tachycardia syndrome (PoTs) in 25%.
- **Gastrointestinal upset** in 41%, including nausea, bowel changes and indigestion.
- **General symptoms.** Including persistent fever in 38%, pain including non-specific chest pain in 60%, rashes in 19% and ongoing loss of smell/taste in 54%.

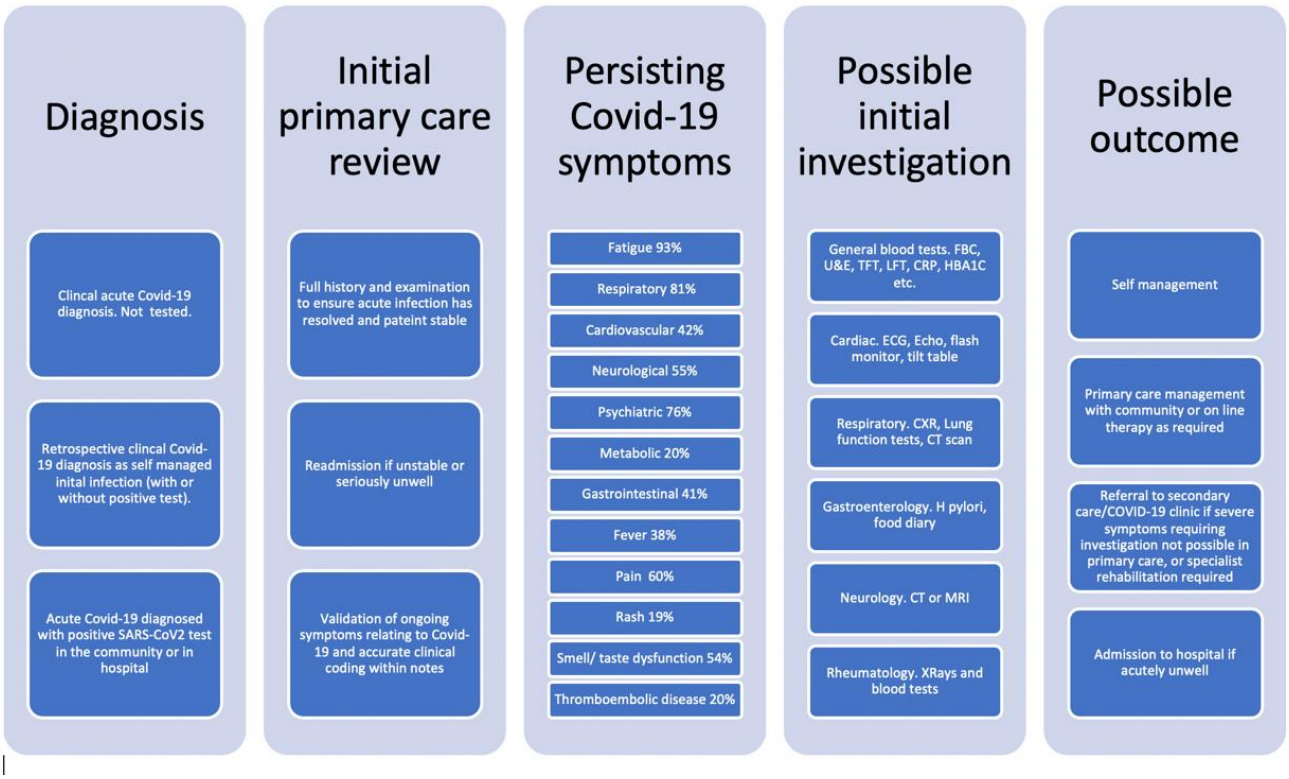
- **Metabolic disruption** in 20%, including worsening diabetic control or worsening of underlying metabolic disease.
- **Psychiatric and psychological symptoms** were described in 76%, which included sleep disorders in addition to mood changes, but it is important to note that until the evidence tells us otherwise, we should always consider whether mood changes are primary symptoms, secondary changes relating to the long term effects of the disease, an adjustment disorder or the adaptation to "being unwell" with the feeling that their COVID-19 illness will "never end".

## 4. Possible investigation and treatment pathway whilst waiting for the national guidance to be produced

*It is essential to exclude underlying pathology and "red flags" that require further investigation and treatment, before a diagnosis of post COVID-19 syndrome is made. Review and investigate the patient, as clinically indicated, at any stage of their illness; you do not need to wait until 12 weeks for this process to begin.*

Before a diagnosis of post COVID-19 syndrome can be made, it is important that other causes of persisting symptoms are ruled out. For example, a patient with a persistent cough may have an underlying cancer requiring a 2 week wait referral; persisting shortness of breath may be heart failure related; a patient with ongoing fatigue may be pregnant, have anaemia, hypothyroidism or uncontrolled diabetes; and a persistent fever may be caused by malignancy or an active infection. Your initial history will narrow down the potential diagnoses with baseline investigations completed to further focus care. Much of this may be completed remotely, but of course face to face assessment may also be clinically indicated, to complete our assessment and plan a treatment pathway. This should be determined by clinical need, using a shared care approach, as we do with all of our patients in primary care. Only once other causes of symptoms have been ruled out, can a diagnosis of post COVID-19 syndrome be made.

A possible pathway, whilst waiting for the full guidance to be produced, for initial primary care review was submitted within the RCGP house of lords report and has been updated below. The initial investigations, which can and should begin before 12 weeks if clinically indicated, will depend upon your clinical assessment, clinical need and will of course be determined by your local offer of diagnostic services for primary care. Only 7% of RCGP survey respondents felt they had good diagnostic testing access within the community for these patients, so whilst some of these tests may be completed by you, they may also require onward referral.




In many areas “post covid” clinics have started to be developed. In September 2020, only 23% of RCGP survey respondents had access to a “post covid” clinic, and shockingly a fifth had access restricted for those patients without a positive SARS-CoV2 test, which we hope will change with the release of the NICE/SIGN/RCGP guideline scope, allowing all of our patients access to appropriate services as they are developed.
Onward referral for treatment to community or secondary care will depend on your patient’s needs. They may be satisfied knowing there is no other underlying cause for their symptoms and opt to self-care, they may require referral to secondary care for further investigation/ treatment, or onward referral to community services, where they exist, for rehabilitation or psychological support.

*NB: Call for investment:* The RCGP has highlighted the need, in it’s house of lords report, for increased long term investment in UK wide primary care services and community diagnostics, access to therapies based in the community, such as physiotherapy, psychology, occupational therapy and specialist rehabilitation, to enable us to provide the best care that we can for patients with ongoing symptoms related to COVID-19 wherever they live.

**5. Other current and upcoming RCGP resources on managing the long term effects of COVID-19**

*We will continue to update the educational information as the evidence emerges and the national guidance is produced in December 2020.*

- **"Save the date" 1st December 2020 at 1900**. Management of the long term effects of COVID-19 webinar. Speakers will include the RCGP clinical policy lead, those with lived experience and academics who have published research in this area.
- The RCGP CPD team have produced 2 e-learning modules, one on recovery from covid-19 and a second called "Long Covid" that cover some of the key learning so far about this condition. Please note that they both pre date the national guidance and will of course be updated once more evidence emerges and the national guidance is released in December 2020.

Date for review: December 2020 once the NICE/SIGN/RCGP national guidance is published.