



Information sheet 6 on COVID-19: Long COVID in East and Southern Africa September 2021

Greetings! This sixth information sheet comes after 18 months of the COVID-19 pandemic in east and southern African (ESA) countries, with many experiencing their third waves of infections and deaths. With such a prolonged pandemic, capacities and understanding have grown around various dimensions of the management of COVID-19, but so too has evidence of social inequities, including the 'moral catastrophe' of a global inequity in access to vaccines. There is now also growing evidence of people who continue experience symptoms more than 12 weeks after their initial infection, or 'long COVID'. This sixth information sheet summarises information on long COVID, and its distribution in the ESA region, responses to it and the equity issues it raises. Previous briefs can be found on the [EQUINET website](#). The information is sourced from United Nations (UN), official, public health, technical/ scientific and other sources. Sources are hyperlinked in the text for you to read further. *The brief complements and does not substitute information from public health authorities and labour organisations.*

In this brief we address four questions and links to resources for this developing field:

- a. [What are the recent trends in COVID-19 in ESA countries?](#)
- b. [What is long COVID and who is affected by it, including in ESA countries?](#)
- c. [What is the response to long COVID, including in ESA countries?](#)
- d. [What equity challenges are raised by long COVID?](#)
- e. [Further resources on long COVID](#)

Key messages

Long COVID, with symptoms that continue for weeks to months after the initial illness is potentially common, but still poorly recognised and monitored in ESA countries. While recognition in higher income countries has grown due to advocacy by people affected by it, the learning and evidence on its causes and consequences are still advancing.

The common symptoms of fatigue, joint and muscle pain, breathlessness, problems with attention, focus and memory and difficulties with exercise or activity, amongst other symptoms, hinder the lives, employment, and psychosocial wellbeing of those affected.

Early detection, recognition and diagnosis are essential for effective management. Care tailored to and paced in line with the symptoms and capacities of those affected is best located at primary care level, supported by medical, physiotherapy, psychology and other skills, and by peer support groups. While there is pilot work and training on this in the ESA region, screening and care services for long COVID are still limited.

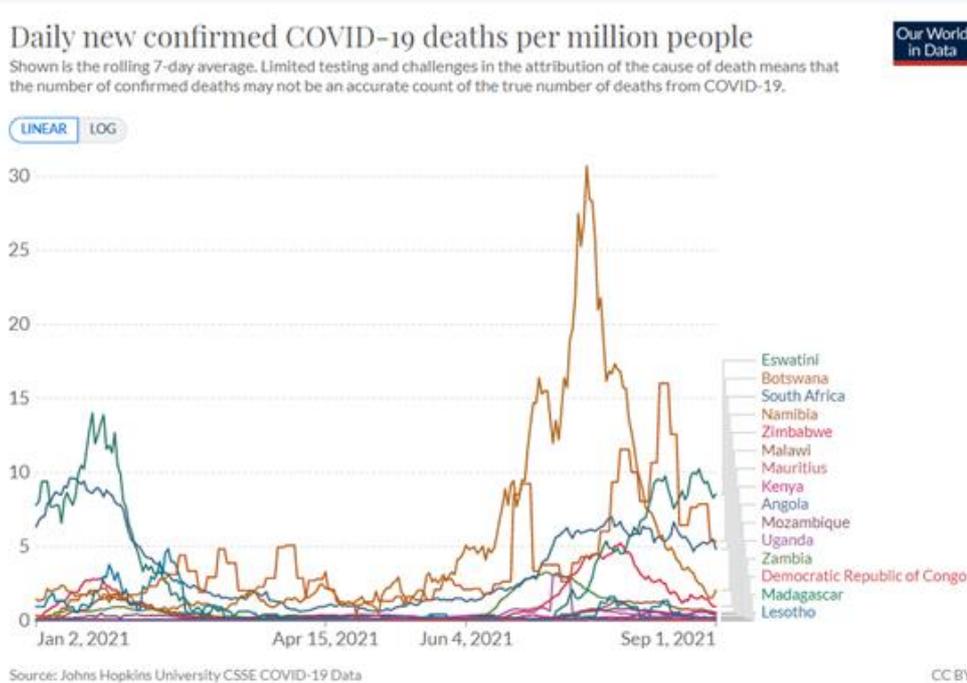
Risk of long COVID is affected by the same socio-economic inequalities that apply to COVID-19, but because long COVID can impede the ability to function, it affects employment, incomes, and domestic life. Together with poor access to appropriate care this can lead to long term socioeconomic consequences. This brief outlines policies and measures to address these inequities and calls for policy, workplace and social recognition of long COVID.

¹ This brief was prepared from a draft of information on long COVID by Dr. Chido Ratidzai Rwafa Madzvamutse, and evidence, inputs and edits by Dr Rene Loewenson, Training and Research Support Centre (TARSC) for EQUINET. The brief was produced in association with the Post COVID Treatment Network - Africa with review input provided by Dr Jonathan Brakarsh. Financial support from Open Society Policy Centre is gratefully acknowledged. Photographs and graphics are used under fair use for educational purposes or under creative commons. If not already subscribed, you can subscribe to EQUINET briefs and newsletters [online here](#).

1. What are the recent trends in COVID-19 in ESA countries?

Figure 1 shows the recent pandemic wave in ESA countries, with rising COVID-19 rates per million, particularly after June 2021. With a more transmissible Delta variant in the majority of cases, daily rates reached higher peaks of infection for many countries than prior waves, particularly in Eswatini, Botswana, South Africa, Namibia, and Zimbabwe (Figure 1). Countries that had previously reported very low rates like Mauritius showed rising infections for the first time. As discussed in previous information briefs, actual rates may be higher than those reported due to barriers in availability of and access to testing.

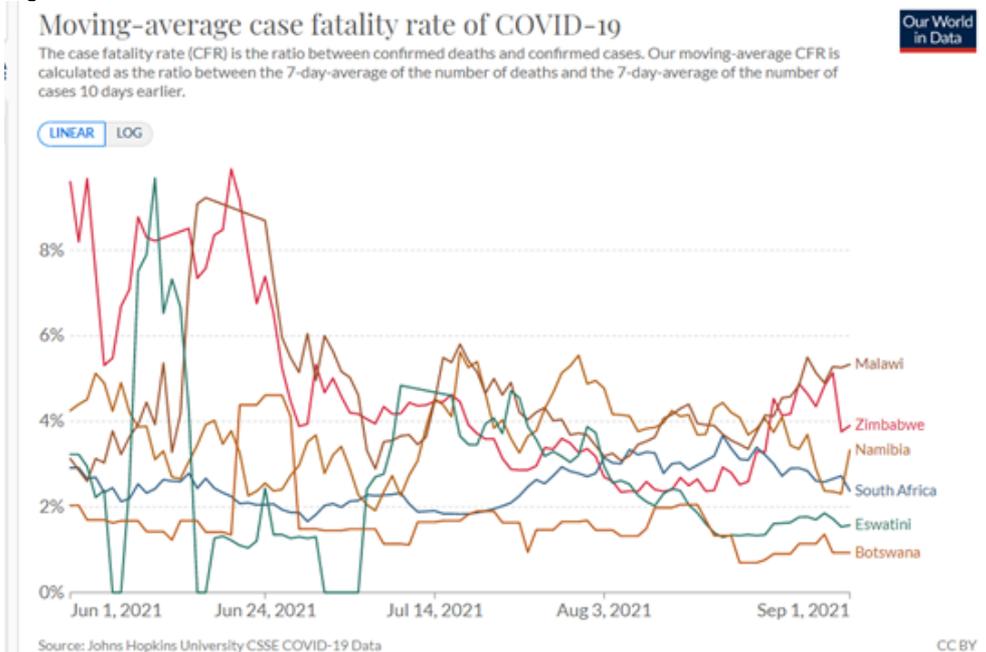
Figure 1:



Source: [Our World in Data 2021](#)

This brief explores the implications of these successive acute waves for their longer term chronic implications. However, there has also been report of rising levels of mortality in the recent wave. Figure 2 shows the case fatality rate for the last 3 months for those countries that had relatively higher infection rates.

Figure 2:

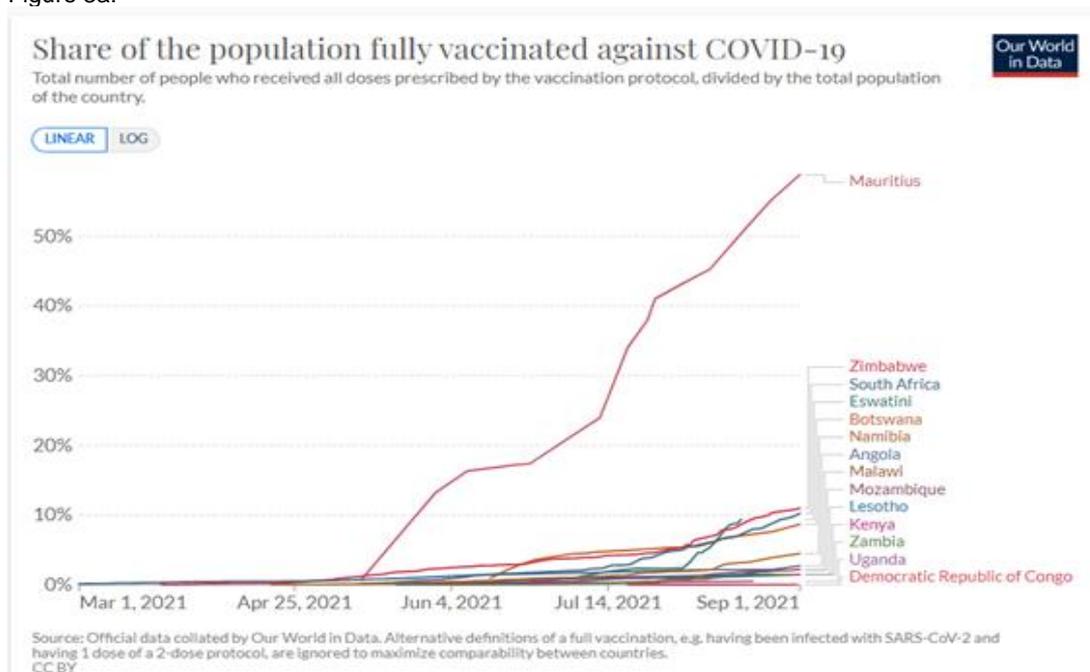


Source: [Our World in Data 2021](#); Malawi 5.33 Zimbabwe 3.90 Namibia 3.33 South Africa 2.37 Eswatini 1.57 Botswana 0.93

As cases are in the denominator of the case fatality rate, not surprisingly the case fatality rate (CFR) fell as cases rose sharply. However, comparing the pattern of deaths against cases across the period of the pandemic raises a question of why the CFR was so much higher at the early stage of the wave in June. Does this suggest still weak outbreak detection, with deaths rather than case detection the first signal of a rising wave?

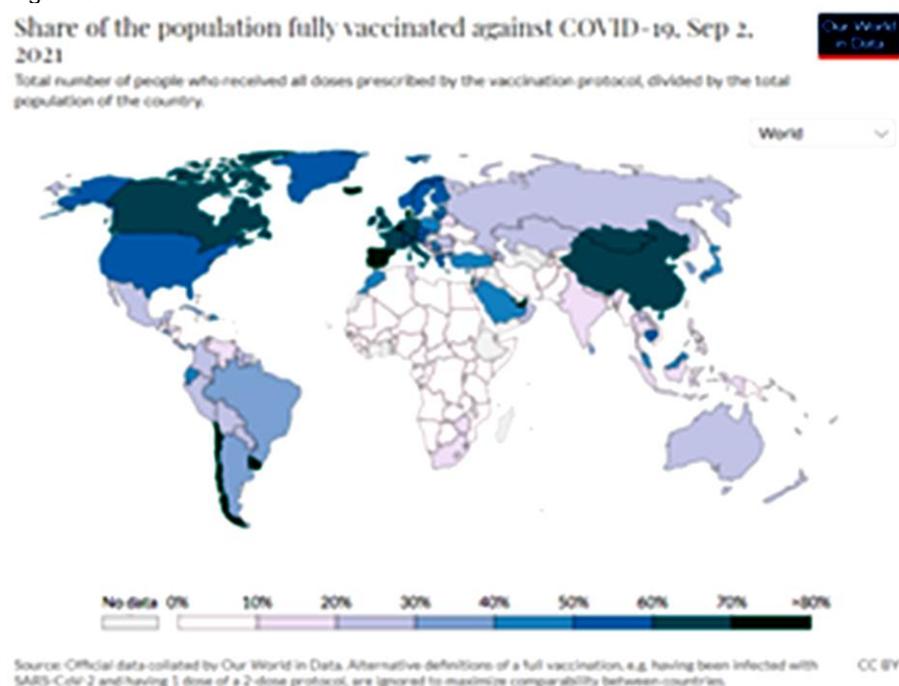
While key social determinants (access to water, crowded housing, safe transport, ventilated workplaces and schools, masks and other protective equipment, clear information and food and social protection) continue to be important issues for prevention and protection responses in the pandemic, the focus in many ESA countries has been on vaccinating populations. However, as *Figure 3a* shows, by beginning September full vaccination coverage remains low in most ESA countries, except for Mauritius, followed at lower levels by Zimbabwe.

Figure 3a:



Source: [Our World in Data 2021](https://ourworldindata.org/covid-vaccines); Mauritius 58.8%, Zimbabwe 10.7% South Africa 9.7% Malawi 2.1% all other ESA countries <2%

Figure 3b:



Low rates of vaccine coverage are primarily a consequence of access to vaccines in ESA countries, as more fully discussed in other EQUINET information briefs. Figure 3b shows the profound global inequity in

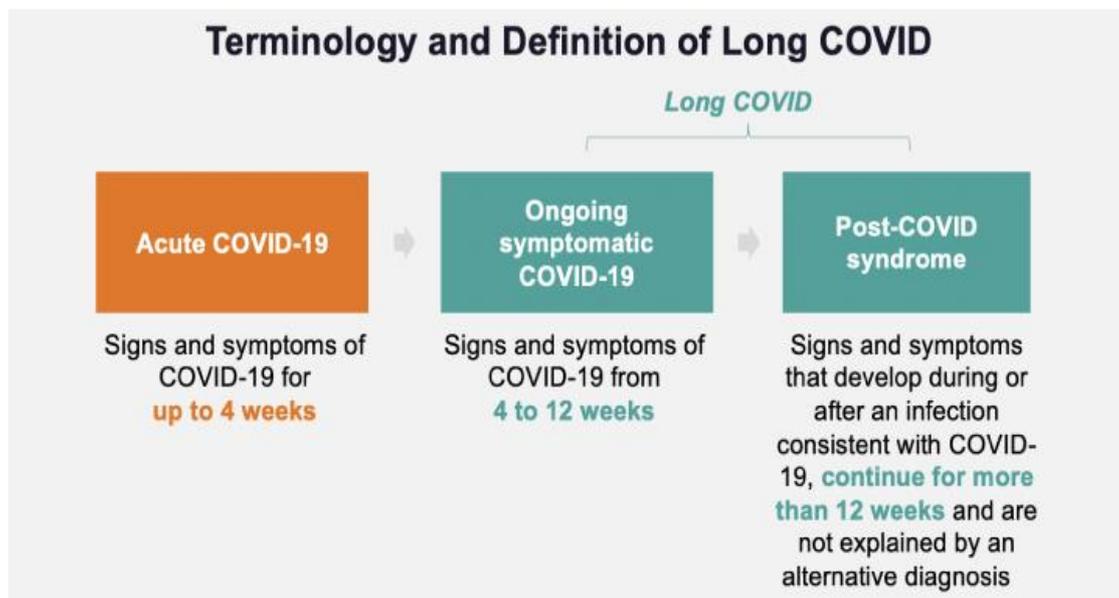
Source: [Our World in Data 2021](https://ourworldindata.org/covid-vaccines)

vaccine coverage.

2. What is long COVID and who is affected by it, including in ESA countries?

While recovery rates from acute infection with SARS-Cov 2, the virus that causes COVID 19 are generally high, some of those infected continue to experience symptoms or recover and then have new symptoms that continue for weeks to months after the initial illness. This longer term, chronic illness is termed [long COVID](#). It is also known as '[long haul COVID](#), [chronic COVID](#), [post-acute sequelae of SARS-COV-2 infection](#) or [post COVID syndromes](#)'.

There is not yet an internationally agreed **definition for long COVID**, however, [guidance from the United Kingdom](#) refers to it as covering symptoms from 4 and 12 weeks after their acute illness (ongoing symptomatic COVID-19) with symptoms that continue for more than 12 weeks after their acute illness (post-COVID-19 syndrome), that cannot be explained by an alternative diagnosis, as shown in the graphic below.



Source: Presentation by Dr Shelton Nash Zichawo, August 2021

People affected by long COVID played a major role in gaining recognition of the condition, after forming support groups and holding grassroots campaigns to raise attention. However, we are still learning about long COVID, and there is particularly limited information and advocacy on it in low and middle income countries. Much of what we know comes from evidence in high income countries.

Long COVID may emerge even after a mild initial COVID-19 infection, and may occur whether the PCR test for SARS-Cov-2 is positive or negative. Studies have different estimates of what share of people with acute COVID go on to develop long COVID, but the share ranges from 20 to 40%. In a [study](#) in the United States, a third of participants had not returned to their usual state of health 2–3 weeks after testing positive, while a [second study](#) in the United Kingdom estimated 20% of those who tested positive for COVID 19 experiencing symptoms for over 5 weeks and 10% for over 12 weeks.

It's not clear why some people go on to have this chronic condition, and this also makes it challenging to manage. There are [hypotheses that the causes](#) relate to direct damage to cells of the body toxicity or a persistent chronic inflammation. It is suggested that it may be due to a continued activation of the immune system even after acute illness, or an abnormal immune, or indeed that it may be a continuation of the viral infection or complications of other pre- existing medical conditions. There are also suggestions that it can be a result of medical factors, including long stays in intensive care and hospital, an effect of medications used during acute illness. It is also suggested that the psychosocial impact of COVID illness may play a role.

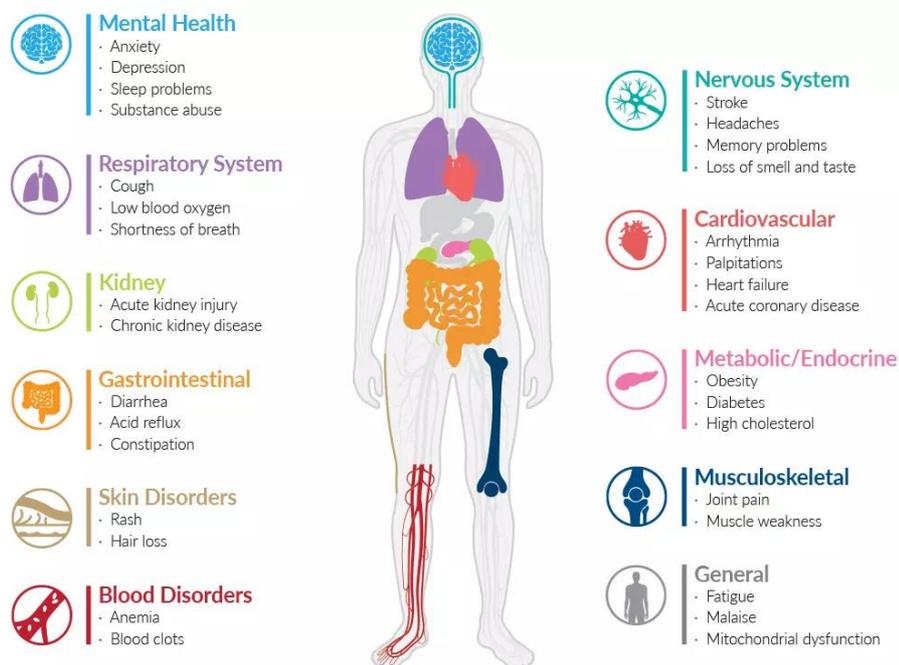
Because the virus causing COVID-19 can affect different organs in the body there are a variety of **symptoms associated with long COVID**, with [one study](#) identifying 200 possible symptoms! The symptoms can be present for weeks or months, even without a positive PCR test, are always prolonged, and may disappear and then re-emerge, and can increase after any sort of exertion.

The more [commonly reported symptoms include](#):

- Fatigue that isn't relieved by rest
- Joint and muscle pain
- Breathlessness
- Problems with attention, focus and memory (sometimes called 'brain fog')
- An inability to exercise or be active

Other symptoms that have been found include

- Depression, anxiety
- Headaches
- Dizziness
- Joint or chest pain
- Coughing
- Sleep disturbances
- Numb, tingling limbs
- Rashes



These symptoms are shown in the above graphic by [Caymenchem, 2021](#).

There is limited evidence on long COVID in the ESA region. Anecdotal and media information from [South Africa](#), [Zimbabwe](#) report similar symptoms to those described above, with four out of ten hospitalized patients in [Nigeria](#) having more than three symptoms for at least two weeks after discharge, and 82% of the 1400 people studied after acute infection in [South Africa](#) having one or more persistent symptoms one month after their initial diagnosis.

The symptoms are classified into different [post-Covid syndromes](#), several of which can exist at the same time in a person. They include:

- a. **Post COVID Fatigue syndrome and musculoskeletal syndrome**, including muscle and joint pain are seen in more than 50 % of survivors, particularly in females. They have been found after other viral infections, and if lasting for more than 6 months may be a form of Chronic Fatigue Syndrome.
- b. **Post COVID Cardio- Respiratory Syndrome**, including breathlessness found in up to 60% of those experiencing long COVID. This is thought to be due to damage or inflammation of the lungs, or of the heart muscles, with possible heart failure. Heart problems are more commonly seen in young men.
- c. **Post COVID Neurocognitive/ Neuropsychiatric Syndrome** includes headaches, anxiety, depression and sleep disturbance in [between 35-48% of people](#) and [loss of sense of smell and attention problems in 21-27%](#) of people. Low mood, anxiety and sleep disturbances are often seen as a cluster, especially in women. Deficits in attention and clear thinking are attributed to possible brain and nerve inflammation.
- d. **Post COVID gastrointestinal Syndrome** includes abdominal pain, diarrhoea, constipation, vomiting as well as jaundice if the liver or bile system is affected
- e. **Post COVID Thromboembolic (Blood Clotting) Syndrome** have symptoms that depend on the area affected, such as breathlessness if the lungs are affected, chest pain if the heart muscle is affected, and limb weakness if the brain is affected.
- f. **Post COVID Genitourinary Syndrome** due to kidney damage.
- g. **Post COVID Dermatological Syndrome** with some having fluid filled, round lesions or itchy lesions particularly on the extremities like toes.

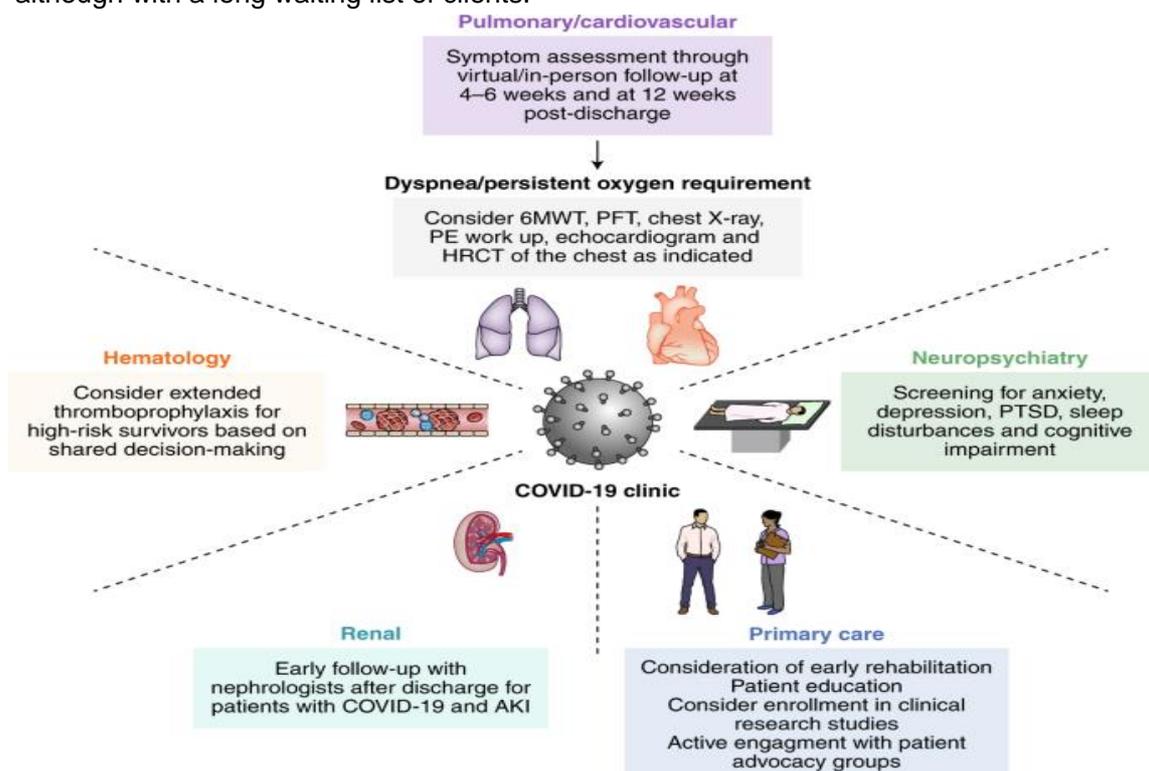
In terms of **who is affected**, few studies have been done in the region, and the understanding of long COVID is still evolving. A [South African study](#) found that long COVID was more likely in people who had had severe disease in the acute phase of illness, particularly when this involved an admission to intensive care; in those who had more symptoms during the acute phase of illness, in women and in those with prior obesity and asthma. Black people were less likely to develop long COVID in that study. [Evidence from high income countries](#) suggests that long COVID may be more likely in women and people who are overweight. In a [study of adults in the USA](#), the number of symptoms during the acute phase seemed a more significant risk factor for long COVID than their severity, with people who had been hospitalized having a greater number of symptoms. Studies in the [UK](#) and [USA](#) suggest that being vaccinated may improve symptoms of long COVID. More information is needed on the [long term effect in children](#).

Recognizing what organs of the body have been affected, how and which of these syndromes people are affected by is important to know to better manage their problems and promote their health

3. What is the response to long COVID, including in ESA countries?

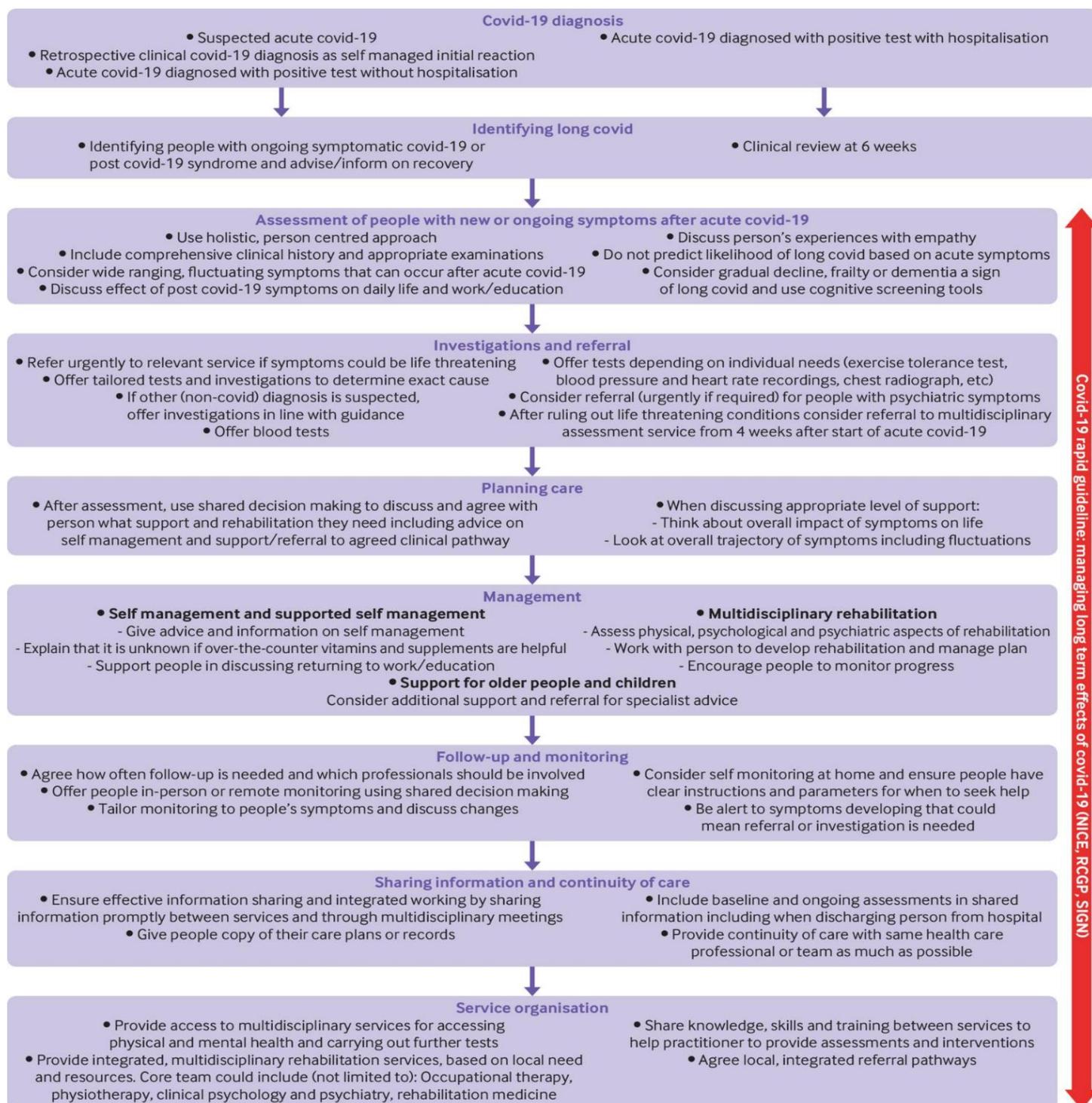
[Recognition of the condition](#) is critical to better management. People with long COVID say that they feel stigmatized and their symptoms trivialized. This can prevent or delay diagnosis. Empathy and validation are thus key, to listen to a person's concerns and exclude other causes of their symptoms. The [World Health Organisation \(WHO\) has guidance](#) for clinicians and patients on the information to collect and report, using a [WHO's Post COVID case report form \(CRF\)](#) 4 to 8 weeks and 6 months after hospital discharge from the acute ward or after acute illness for individuals who have not been hospitalized, and then three-monthly if symptoms persist or 6 monthly if not.

Patients in high and low income settings report that **care for long COVID** is often fragmented and siloed. Care should ideally be multidisciplinary, involving different medical personnel (internal medicine, physiotherapy, psychology, psychiatry and occupational therapy). Some high income countries have set up [long COVID clinics](#) to see people referred by their general practitioners and or discharged from hospital, although with a long waiting list of clients.



Interdisciplinary management in COVID-19 clinics [Nalbandian, et al., 2021](#)

National Institute for Health and Care Excellence guidelines show stages for management of long COVID 19, outlined in the graphic below.



Covid-19 rapid guideline: managing long term effects of covid-19 (NICE, RCGP, SIGN)

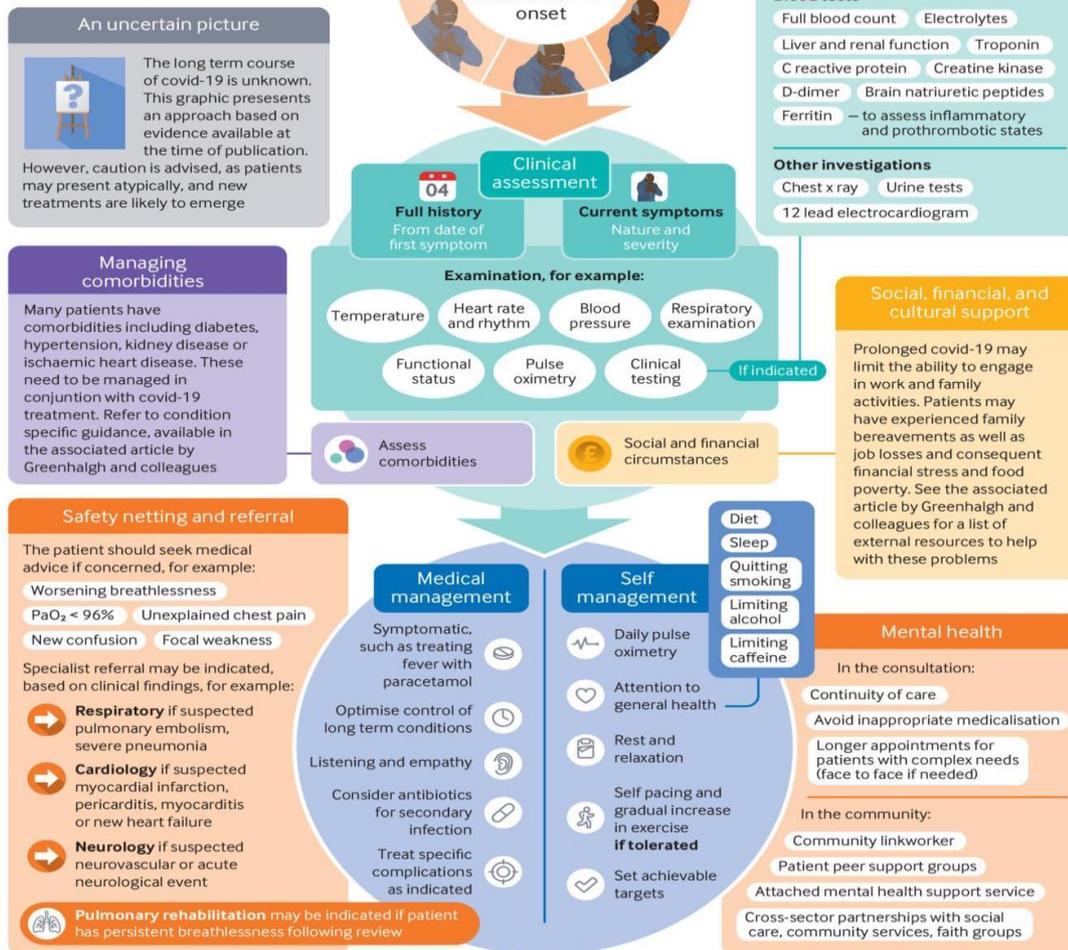
NICE rapid guideline: managing the long term effects of covid-19 [Crook et al., 2020](#)

Given the chronic nature of long COVID, [high income countries](#) have proposed placing **care in primary care clinics and in the community**, and using structured primary care visits at 4 weeks, 8 weeks and 12 weeks post diagnosis guided by treatment algorithms for the various symptom clusters of long COVID. Improving access to primary health care supported by a multi-disciplinary team is suggested to improve equities in coverage and support frontline health workers manage the multiple dimensions of long COVID, as summarized in the graphic below from BMJ.

“Long covid” in primary care

Assessment and initial management of patients with continuing symptoms

Post-acute covid-19 appears to be a multi-system disease, sometimes occurring after a relatively mild acute illness. Clinical management requires a whole-patient perspective. This graphic summarises the assessment and initial management of patients with delayed recovery from an episode of covid-19 that was managed in the community or in a standard hospital ward.



thebmj Read the full article online <https://bit.ly/BMJlong>

© 2020 BMJ Publishing Group Ltd. Disclaimer: This infographic is not a validated clinical decision aid. This information is provided without any representations, conditions, or warranties that it is accurate or up to date. BMJ and its licensors assume no responsibility for any aspect of treatment administered with the aid of this information. Any reliance placed on this information is strictly at the user's own risk. For the full disclaimer wording see BMJ's terms and conditions: <http://www.bmj.com/company/legal-information/>

See more visual summaries <http://www.bmj.com/infographics>

Long COVID in primary care [BMJ, 2020](https://doi.org/10.1136/bmj.n1000)

Primary care support offers possibilities for connecting with **person-centred related services** for long COVID, involving physical rehabilitation, psychological, medical and social support. This includes

- Rehabilitation involving light aerobic exercise paced according to individual capacity gradually increasing the level of exertion over four to six weeks, and breathing exercises use slow, deep breaths to strengthen respiratory muscles' efficiency. These activities are carried out in small chunks with rest or relaxation in between to avoid worsening fatigue and enable people to live within their “energy envelope”, gradually decreasing symptoms.
- Provide psychosocial support through teaching strategies for managing anxiety, irritability, frustration, and sadness and to provide compensatory strategies and routines.
- Monitor and support physical wellbeing in terms of heart rate monitoring; respiratory retraining; progressive muscle and ergonomic relaxation; and muscle and joint pain relief techniques.

- [Provide medications](#) for treatment tailored to the case as relevant to address specific symptoms, including for insomnia and for post Covid fatigue. A number of [emerging treatments, supplements and repurposed medications](#) are being investigated as possible treatments for long COVID, and methods such as breathing exercises with singing to treat breathing problems.

There appears to be limited **screening and treatment for long COVID in the ESA region**, and current treatment approaches are fragmented and siloed, usually involving multiple specialists working in isolation from each other. There is increasing recognition for the need for a more multidisciplinary approach, including rehabilitation and psychological input. This may call for training in long COVID treatment approaches.

There is, however, increasing recognition of long COVID among health workers and policymakers and some innovations that could provide learning for other countries. [In Cape Town, South Africa Post COVID follow up clinics](#) have been set up, with a multi-disciplinary approach with rehabilitation specialists, psychological input and pain specialists. Care in the community and in the primary care system with a stepped care approach where more complicated cases are referred up the referral system, is suggested to be a more cost effective approach in resource limited settings. There are ongoing studies following up patients who had COVID to assess the progression of long COVID in the African setting, to help develop treatment guidelines, drawing on international guidelines noted earlier, and to empower and train health care workers. [Treatment networks](#) and informal networks of medical professionals could also help coordinate services and provide support for healthcare workers as they care for people with long COVID.

A [recent webinar](#) hosted by the Post COVID Treatment Network -Africa and African Mental Health Research Initiative (AMARI) raised awareness on long COVID and its management. The speakers raised similar multidisciplinary team and primary care and community –based processes and the spectrum of interventions as raised in this section. One challenge with implementing these responses to long COVID is the affordability of these services when privately provided and the resources for them in public, primary care services. This is particularly the case given the need for individualised treatment plans, and the constraints to managing this given the limited service providers and specialists, gaps in health service infrastructure; lack of information and evidence directly from the region to innovate and test transferability of approaches being applied in other regions.

The psychosocial impact of long Covid, including on mental health, daily life, work, education and incomes, has motivated [patient-led advocacy and self help groups](#). Online support and self-help groups have played a critical role in raising awareness about long COVID, giving a voice to those affected, enabling peer support and supporting nutrition, sleep and stress reduction, including through meditation. Some have medical professionals available to provide advice.

Some of these support groups are listed below

- [COVID Advocacy Exchange](#)
- [National Patient Advocate Foundation COVID Care Resource Center](#)
- [Body Politic COVID-19 Support Group](#), that also engages with researchers forming [patient led research collaborations](#).
- [Survivor Corps](#)
- [C19 Recovery Awareness](#)
- [Patient-Led Research for COVID-19](#)
- [COVID support group](#) on Facebook

There is a growth in online support groups for long COVID. In the region they include

- [Facebook support groups](#) in Kenya, South Africa, Malawi, and Nigeria.
- A [Long Haul COVID Support Africa](#) Facebook page has been formed as a self help platform

There is also on Linked-in a [Health Professionals Forum: Post Covid Treatment in Africa](#) to support health workers.

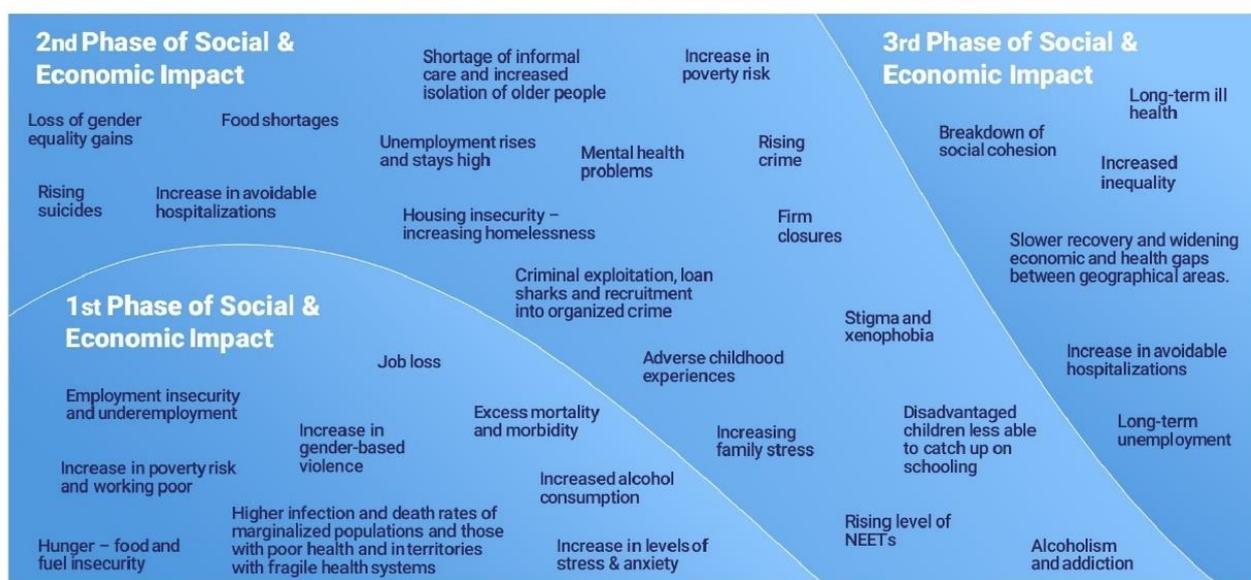
4. What equity challenges are raised by long COVID?

Previous [EQUINET information briefs](#) have explored the many dimensions of inequity raised by the pandemic. There are social inequalities in exposure to SARs-Cov-2 due to the increased risk that some workers, community members and social groups have as a result of living, working and social conditions that increase their possibility of infection, and now due to inequities in access to vaccines. There are social inequalities in the impact of infection and severity of disease, not only due to multiple exposures, but also due to background conditions, and access to quality food, care and social protection. This impact can be longer term, as severe illness and mortality affects education, employment, incomes for those directly affected and their families, particularly in the absence of adequate social protection. These inequalities are clearly also *inequities* when those who are at greater risk also have less access to social measures to prevent COVID disease or its impacts and consequences.

[Long COVID reflects these social inequalities and inequities](#). Increased risk of exposure from multiple levels of deprivation may mean that people are exposed multiple times to higher levels of viruses, increasing their risk of severe disease and thus long COVID. Older people and those with co-morbidities are also at greater risk of long COVID, especially when other chronic conditions are poorly recognised or managed, as is the case in many low income communities. The same challenges in living, working and social conditions (lack of decent housing, food, fuel, lack of education, living in unsafe neighbourhoods and long commutes or crowded transport) that raise the risk of exposure to COVID can also make it more difficult to manage the mental, physical and social features of long COVID.

Apart from its direct impact on health due to several persistent symptoms, long COVID can impede a person's **ability to function and continue their usual activities**. They may face challenges with exercise and movement, and with the energy, attention and mental demands for work and home. Women more affected by fatigue and energy loss, as noted earlier, so there may be a gender inequality in this impact that further disadvantages women who already face socio-economic barriers and demands in both informal employment and long days of domestic work and caring in the home. Workers who have to walk long distances to reach workplaces or work under stressful conditions may also face greater challenges in coping with the energy and mobility losses, while other groups, including in high skills occupations may face challenges from attention and cognitive losses. *The more individuals, communities and sectors are aware of long COVID and its management, the more likely that these demands can be recognised and acted on and the support provided to manage them..*

The socio-economic impacts of COVID are wide, and can be located in different phases and at different and widening levels, as the graphic below from WHO Euro presents. Prolonged symptoms and disability from long COVID contributed to this.



Note: NEET: young person not in education, employment or training.

Source: [WHO Regional office for Europe, 2020 p2](#)

Workplaces are a key site of equity in the response. While there is still limited evidence from ESA countries, there is some evidence from the studies noted earlier that those experiencing long COVID report a [change in employment status or employment loss](#) due to the long duration of illness and decreased functioning. Workplaces in various countries are however beginning to recognize the [impact of long COVID in the workplace](#). In [South Africa](#) some employers are reported to be redefining the parameters for sick leave in the context of long COVID to address the time needed for recovery, with some considering allowing a slower return to work, adjusted duties and adjusted working hours.

The socio-economic impacts may be more profound in those most affected by long COVID, including older patients: who often are financially vulnerable and may not have equitable access to treatment as younger family members; people with pre-existing illnesses such as obesity, hypertension and diabetes who often come from more disadvantaged socioeconomic conditions and may lack access to health care, including more disadvantaged women and youth, migrant workers, those on precarious contracts, students, and people living in a range of situations of deprivation.

For groups more at risk of long COVID, access to the range of services outlined earlier for physical, psychosocial, medical and group support is even more important, and particularly in the public sector primary care and social services and community health systems more commonly used by disadvantaged groups. Prior EQUINET briefs have, however, already noted inequities in access to and deficits in the services needed in ESA countries. This is potentially even greater when considering the more multidisciplinary support for primary care management of long COVID, with [health care access inequities](#) from diagnosis through to long term management. Beyond the barriers to access and financial hardships caused by charges, there are concerns about the different quality of care received by different social and income groups.

This starts with **inequities in early detection and diagnosis, and continues in the inequities in long term care**. Although now not considered a prerequisite for diagnosing long COVID, PCR and antibody tests can be beyond the financial reach of many if not offered free of charge. As noted earlier, long COVID is a diagnosis reached by excluding other problems, and this requires multiple visits to health facilities and numerous investigations for appropriate diagnosis and ruling out alternative diagnoses. Following this, *the knowledge and capabilities for managing the care and rehabilitation needs of long COVID, described earlier, still need to be built in in community and primary care systems in ESA countries.* There is some synergy in doing this with building the capacities and systems for managing other chronic conditions (NCDs). Health systems that are fractured, with limited investment in primary health care and different disciplinary capacities are poorly equipped to manage long COVID, as for other NCDs. In countries where the consequences of long COVID are being recognized, there are [recommendations](#) to *create more inclusive disability policies that recognize long-COVID as a health condition, co-ordinate and fund responses, implement a robust, national communication and education campaign, and provide public evidence on interventions.*

Equitable care for and recovery from long COVID also demands holistic, **person centred approaches**, where the person's role, quality of life and their social and family support are important in the therapy. The lack of awareness, stigmatization and trivialization of symptoms noted earlier to be faced by those living with long COVID can undermine this.

Inequities can be addressed by raising awareness concerning Long COVID. [Advocacy groups and support groups](#) can play a role in this. They can raise, discuss and suggesting ways of addressing challenges and equity concerns, including health financing needs, and social encouragement and support. Further those affected in the ESA region when organized collectively will play a key role, as they have done in other countries, in expanding knowledge and policy recognition, as [key advocates, collaborators and partners](#) in advocacy, research, policy and prevention and care guidelines for this condition. While recognised by the WHO, it is now time for African governments and continental and regional communities (SADC, EAC, ECSAHC, Africa CDC, AU) to recognize and respond to long COVID, and its implications for (in)equity.

5. Further resources on long COVID

Click on the hyperlinks in the different sections of this information brief to read more from the document resources included on the issues and information included in this brief.

A webinar on Long Covid in Zimbabwe: Treatment and Challenges was held on August 11, 2021. You can listen to it at https://www.youtube.com/watch?v=AWPYM_qrGul



There are also videos of webinars on long COVID from other countries, such as:

- A [health24 South Africa](#) broadcast on research on long COVID
- A [BMA hosted an online webinar](#) on long COVID
- A [WHO Euro statement](#) on a patient centred approach to managing long COVID
- A [National Institute of Occupational Health South Africa](#) video on long COVID at the workplace
- A [BBC Panorama](#) on one journalist's experience of long COVID

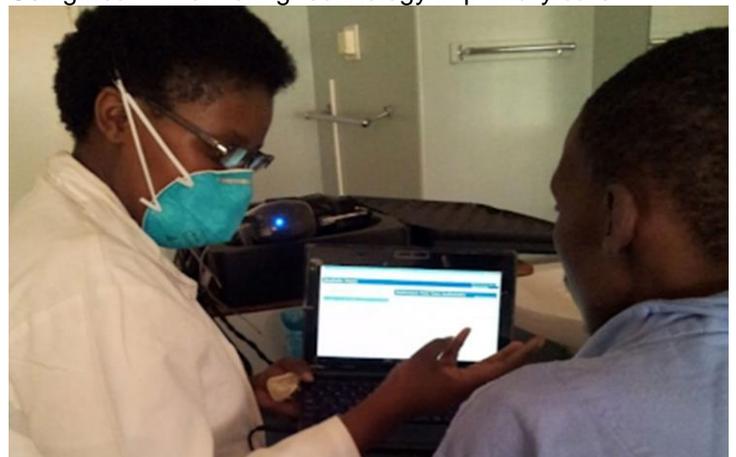
Those living in Africa with long COVID have the option of joining the online support groups shown in the earlier section, such as the [Long Haul COVID Support Africa](#), with the web page in the hyperlink providing information on the self-help / support platforms in different countries.

For Health Professionals, there is a LinkedIn group [Health Professionals Forum: Post Covid Treatment in Africa](#)

There are also a range of online video and online resources to support health professionals in managing long COVID, such as:

- A [WHO Science episode](#) on Post COVID-19 condition
- A [BMJ Practice pointer](#) on management of post-acute COVID-19 in primary care
- A [Free Physiospot Course](#) on long COVID
- [Online courses for various professionals on COVID](#) from Knowledge Management South Africa
- [NICE UK Rapid Guidance](#) on managing long term effects of COVID

Using health monitoring technology in primary care



Source: [T Quine, South Africa](#), 2021 under CC

With knowledge and experience in long COVID constantly developing, the best resource appears to also be listening to and sharing the experience of and learning from those with the condition, and those supporting them.