Cabinet Secretary for Health and Social Care Humza Yousaf MSP



T: 0300 244 4000 E: scottish.ministers@gov.scot

Siobhian Brown MSP Convener COVID-19 Recovery Committee Scottish Parliament Edinburgh EH99 1SP

By email COVID19.committee@parliament.scot

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Dear Convener

Thank you for your letter of 25 November 2022, requesting information in relation to the Committee's forthcoming inquiry into long COVID. I have provided information on each of these areas below, which I hope is helpful for yourself and the wider Committee.

## 1. Further information on the £2.5 million supported nine research projects commissioned by the Scottish Government into long COVID;

As part of the Scottish Government's response to the pandemic, the Chief Scientist Office (CSO) launched a funding call in October 2020, seeking applications for research to investigate the longer-term effects of COVID-19. Following an independent expert review process, nine projects were funded with a total funding commitment of around £2.5 million. The funding outcome was <u>announced</u> in December 2020 and includes projects to better understand the symptoms of, and factors associated with, long COVID, to examine effects on cognitive function, and to evaluate rehabilitation approaches.

The nine projects are all progressing and are at around the mid-point stage of their 22 to 24 months duration. The full outputs from these projects are expected once they have been fully completed. However, some have reached a stage where it has been possible for the research teams to publish initial findings in peer-reviewed scientific journals, including a number of papers describing the nature of, and factors associated with, long COVID. These include results suggesting that asymptomatic infection is not associated with adverse outcomes and that COVID-19 vaccination may be associated with reduced risks of some symptoms.

I can share some examples of the papers which have been published:

• Hastie *et al.* (2022) Outcomes among confirmed cases and a matched comparison group in the Long-COVID in Scotland study. Nature Communications. <u>Outcomes</u>

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among confirmed cases and a matched comparison group in the Long-COVID in Scotland study | Nature Communications)

- Hayes *et al.* (2021) More Than 100 Persistent Symptoms of SARS-CoV-2 (Long COVID): A Scoping Review. Frontiers Medicine. <u>Frontiers | More Than 100 Persistent</u> <u>Symptoms of SARS-CoV-2 (Long COVID): A Scoping Review (frontiersin.org)</u>
- Healey *et al.* (2022) Symptoms and signs of long COVID: A rapid review and metaanalysis. Journal of Global Health. <u>Symptoms and signs of long COVID: A rapid</u> <u>review and meta-analysis — JOGH</u>

# 2. Details of funding allocations of the £10 million long COVID support fund to date and future investment plans for addressing long COVID;

We have made an initial £3 million available from our £10m long COVID Support Fund over the financial year 2022-23 to provide NHS Boards and partners with additional resource to respond to the needs of people with long COVID in their areas.

The table below outlines the organisations to which funding has been made available for 2022-23, and the associated amounts.

Organisation	Funding amount made available (£)
NHS Ayrshire and Arran	187,554
NHS Borders	50,727
NHS Dumfries & Galloway	79,426
NHS Fife	178,051
NHS Forth Valley	142,020
NHS Grampian	254,847
NHS Greater Glasgow and Clyde	595,169
NHS Highland	119,641
NHS Lanarkshire	320,007
NHS Lothian	372,215
NHS Orkney	14,716
NHS Shetland	13,676
NHS Tayside	194,620
NHS Western Isles	19,988
NHS National Services Scotland	370,000
Thistle Foundation	87,343
TOTAL	3,000,000

Further detail on the initiatives that this funding is being used to support can be found in Annex A.

We remain committed to delivering the £10m Long COVID Support Fund and the 2023-24 budget published on 15 December 2022 outlines that £3m will be made available from the fund over the financial year 2023-24.

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# 3. Further details on the expert group set up to identify the capacity needs of NHS Boards and staff in supporting people who have long COVID;

To complement activity already taking place at a national and individual NHS Board level, the Scottish Government commissioned NHS National Services Scotland to establish an expert short life working group on managing the long-term effects of COVID-19.

The short life working group met in September and November 2021, and recommended that the most appropriate model to support the development and implementation of the approach outlined in the Scottish Government's publication <u>Scotland's long COVID Service</u> would be the establishment of a National Strategic Network. This recommendation was agreed by NHS Board Chief Executives on 11 January 2022.

The National Strategic Network was established in March 2022 to provide national support to building the capacity, capability and co-ordination of health and social care services for people with long-term effects of COVID-19. The Strategic Network structure is composed of:

- A strategic oversight board
- A steering group
- A clinical and subject matter expert group
- A service planning group
- A lived experience planning group

## 4. An update on the implementation of the recommendations of the National Strategic Network on the initial priority areas for improvement in relation to long COVID

The National Strategic Network conducted survey and gap analysis exercises which identified the following priority areas for improvement activity.

## Additional resource to allow time to be spent on holistic assessment and support of people with long-term effects of COVID-19

As outlined in response to question 2, funding has been made available to NHS Boards and partners to respond to the needs of people with long COVID in their areas. NHS Boards are using the resource to develop pathways which aim to support early intervention and improved co-ordination of support and services for people with long COVID.

For example, many Boards are introducing a single point of access for assessment and coordinated support from services including physiotherapy, occupational therapy and psychology, depending on what is most appropriate for a person's needs.

In addition, the Strategic Network is conducting a procurement exercise to enable a digital tool to be made available throughout Scotland to support the collection of patient reported outcome measures that can be shared with their clinicians to inform the planning of care and support.

#### Support for professional education

The Strategic Network has developed and is implementing an education strategy to raise awareness of the long-term effects of COVID-19, share education resources related to



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symptom management, and share developing knowledge and expertise across healthcare professionals working with people with long-term effects of COVID-19.

This has been supported by the establishment of a bi-monthly peer support forum, and will be supplemented by the development of a quarterly multi-disciplinary case conference for complex cases and a central web-based resource for sharing information and signposting to learning resources.

#### Consolidation of clinical pathways

The Strategic Network has established a clinical and subject matter expert group, bringing together professionals from different disciplines with expertise in the management of symptoms associated with long COVID.

The group is currently collating information on existing pathways of care for the management of symptoms associated with long COVID, and will support the development of standardised guidance as required where variation in practice is identified.

#### Ongoing engagement with people with lived experience

The Strategic Network has established a lived experience planning group to co-ordinate activity to support the engagement of people with lived experience, and ensure their views inform development of pathways of care and support.

The Health and Social Care Alliance Scotland (the ALLIANCE) has been commissioned to facilitate a lived experience network to gather views from a range of people with experience of long COVID, and those supporting them. This network was launched in August 2022, and has completed a survey exercise to identify priorities from people with lived experience of long COVID.

#### Evidence and innovation

The Strategic Network is facilitating the exchange of regular updates to clinical and service planning colleagues to ensure they have access to up to date and evidence-based information to inform practice and planning, including relevant information from CSO funded studies on the long-term effects of COVID-19.

A programme of quarterly knowledge-sharing events has been initiated to achieve this, and will be supported by the publication of a monthly bulletin summarising key updates.

#### Data and intelligence

The Strategic Network is undertaking a work stream to facilitate a consistent national approach to the collection of data relating to long COVID, that allows for comparative analysis across Scotland.

A workshop has been held with key stakeholders to identify data collection needs and further activity is planned to determine and agree recording and reporting mechanisms required at local and national levels.

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# 5. Further details on the £370,000 supported national programme of improvement work led by National Strategic Network

In May 2022, a total of £370,00 was made available within the long COVID Support Fund for 2022-23 to support the delivery of the national level activities outlined in response to question 4.

This included making £200,000 available to support the procurement and supply of a digital tool to support the collection of patient reported outcome measures, and £170,000 to support the operation of the Strategic Network. The costs of the Strategic Network mainly reflect the staffing costs to deliver the programme of work, including costs for providing sessions for clinical leadership where required.

# 6. How the Scottish Government is meeting the recommendations of NICE around long COVID service provision.

The clinical guideline on managing the long-term effects of COVID developed by the Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners (RCGP) makes the following recommendations in relation to service organisation;

#### Agree local, integrated referral pathways between primary and community care, rehabilitation services and specialist services, multidisciplinary assessment clinics (where available) and specialist mental health services.

A clinical and subject matter expert group has been established through the Strategic Network to support the implementation of the clinical guideline within NHS Scotland and provide information and support where required to NHS Boards on the development of local referral pathways for long-term effects of COVID-19.

# Share knowledge, skills and training between services to help practitioners in the community provide assessments and interventions, such as 1-minute sit-to-stand tests and breathlessness training.

The Strategic Network has developed and is implementing an education strategy to raise awareness of the long-term effects of COVID-19, share education resources related to symptom management, and share developing knowledge and expertise across healthcare professionals working with people with long-term effects of COVID-19.

Provide integrated, multidisciplinary rehabilitation services, based on local need and resources. Healthcare professionals should have a range of specialist skills, with expertise in managing fatigue and respiratory symptoms (including breathlessness). Additional expertise may be needed depending on the age and symptoms of the person. The core team could include, but not be limited to, the following specialist areas:

- occupational therapy
- physiotherapy
- clinical psychology and psychiatry
- rehabilitation medicine.

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The Scottish Government has made resource available to NHS Boards through our long COVID Support Fund which is being used to augment and provide access to the services outlined in the guideline recommendation above. For example, many Boards are using the funding to introduce rehabilitation pathways providing a single point of access for assessment and co-ordinated support from services including physiotherapy, occupational therapy and psychology, depending on what is most appropriate for a person's individual needs.

Provide access to multidisciplinary services, if available, (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. Services should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms.

The rationale in the guideline related to this recommendation notes that due to geographical factors and the differing needs and resources of areas "one model would not fit all areas" and that 'one-stop' clinics "*might not be feasible for all services or wanted by all patients*".

As noted as an option within the clinical guideline, NHS Scotland Boards are providing assessment and support for people with long COVID through integrated and co-ordinated primary care, community, rehabilitation and mental health services, with referral for further investigation in secondary care settings where clinically necessary.

# 7. Clarification on its position on long COVID clinics and information on which, if any, health boards have established them:

It is for each NHS Board to develop and deliver the best models of care for assessment, diagnostic tests, and support for the treatment or management of symptoms, tailored to the needs of their local population. This may involve strengthening the co-ordination of existing services, or establishing dedicated services where appropriate.

While none of the services being delivered by NHS Scotland Boards are termed 'long COVID clinics', initiatives being supported by the funding include key elements of care that are also offered by post COVID assessment clinics elsewhere in the UK, including pathways providing assessment and co-ordinated access to relevant support and services in line with individual patient needs.

#### 8. Details of those people who have accessed Chest, Heart and Stroke Scotland's 'long COVID support services'

As of the end of November 2022, a total of 3,444 referrals were made to Chest, Heart & Stroke Scotland's long COVID Support Service since its inception in February 2021.

Data collected by the charity shows that from September 2022 to the end of November 2022, a total of 113 hours and 5 minutes were spent on calls. 92% of all calls required information on pacing, fatigue, sleep, diet and return to work issues as a combination within each call.

## <u>9. Whether the Scottish Government believes long COVID should be treated as a disability under the Equality Act 2010;</u>

The subject matter of the Equality Act 2010 is largely reserved to the UK Government. A person is disabled under the Equality Act 2010 if they have a physical or mental impairment

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that has a 'substantial' and 'long-term' adverse effect on their ability to do normal day-to-day activities.

If long COVID has this effect on an individual they would meet the definition of disability in terms of the Equality Act 2010.

I hope you find the information outlined in this letter to be helpful.

Yours sincerely,

**HUMZA YOUSAF** 

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# ANNEX A – 2022-23 Funding made available through long COVID Support Fund and initiatives this funding is supporting

## NHS Ayrshire and Arran, £187,554

- Development of a long COVID multidisciplinary rehabilitation pathway delivering a single point of access for assessment and co-ordinated support from services including physiotherapy, occupational therapy, and psychology, depending on what is most appropriate for a person's needs.
- Liaison with primary care, third sector community support services and where required, onward referral to specialist clinical pathways via normal routes and triage processes.
- Support is currently being provided to people who require this due to long COVID via services already established in the community depending on their symptoms. For example, this may include primary care services, secondary referral to specialist services e.g. respiratory or cardiology pathways, or referral to intermediate care or rehabilitation services. Staff in these services have received specialist training in the management of long COVID, and there is a small cohort of staff supporting people deemed at most need by their general practitioners on a case by case basis, dependent on availability of staff.
- Support is also being provided to NHS staff who are experiencing symptoms of long COVID. This is primarily provided in occupational health by a specialist physiotherapist, using a long term conditions rehabilitation approach.

#### NHS Borders, £50,727

- Development of clear and easy to access pathways for those requiring support for long COVID. These pathways will be developed by an advanced practice occupational therapist based in primary care alongside clinicians from other specialties.
- Support is currently being provided for those with long COVID through existing services in line with presenting symptoms. This may mean support from GP, cardiology, respiratory, physiotherapy, occupational therapy or psychology services as appropriate.

#### NHS Dumfries and Galloway, £79,426

- Establishment of a small team of experts to lead on the long COVID Rehabilitation Service development. This includes a Lead GP, AHP, Psychologist and Public Health Practitioner.
- Support is currently being provided for people with long COVID by services which were established for people suffering from ME/CFS/Fibromyalgia. GPs can refer to psychology, AHPs and, if necessary specialist secondary care services. In due course the Board intend to unify these services into a more bespoke, streamlined service.

## NHS Fife, £178,051

• Development of a long COVID rehabilitation pathway, delivering a point of access for assessment and co-ordinated support from services including nursing, physiotherapy,

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occupational therapy, and others depending on what is most appropriate for a person's needs.

• Support is currently being provided to people who require this due to long COVID via services already established in the community depending on their symptoms. For example, this may include community rehabilitation teams, chronic fatigue service, pulmonary rehabilitation and other services.

## NHS Forth Valley, £142,020

- Development of a screening service for people referred with long COVID and recruitment of an Allied Health Professional long COVID Coordinator, a Clinical Associate in applied Psychology, a full-time Respiratory Physiotherapist and a parttime Psychologist.
- The screening sessions will provide screening and signposting as well as offering supported self management groups.
- The long COVID Coordinator will be responsible for the mapping of services and supporting healthcare professionals' understanding of referral pathways available to support patients with long COVID. The Coordinator will support the development of local networks, and the organisation and delivery of training, to ensure that guidance, tools and pathways are shared throughout General practice, primary and secondary care.
- A long COVID pathway is already in place to support referrers in decision making when people present with long COVID symptoms. There is access to supported self management resources and referral to specialist services based on people's specific and individual needs.

## NHS Grampian, £254,847

- Development of a long COVID rehabilitation pathway embedded within existing services, including supported self management, specialist advice for patients and other professionals, onward referral to appropriate services for investigation or treatment, and may include a single point of access for assessment and co-ordinated support, depending on what is most appropriate for a person's needs.
- Identifying and responding to training needs of the wider workforce in health and care in relation to managing long COVID.
- Support is currently being provided to people who require support due to long COVID via existing services in secondary care, primary care and in the community depending on their symptoms and needs. For example, this may include General practice, occupational therapy, physiotherapy, psychology or specialist services.

## NHS Greater Glasgow and Clyde, £595,169

- Development of a long COVID rehabilitation pathway, implementing a single point of access for assessment and co-ordinated support. This service model is focussed on Occupational Therapists delivering specialist assessment to those presenting with the common symptoms of long COVID.
- This service will be a primary care service, accessed via referral from GPs and secondary care. As such, it will liaise closely with primary care and community health and locality services referring to specialist services where required.

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- Interventions provided will include virtual and telephone assessment, signposting to online and digital resources and support to utilise these, as well as virtual and face to face group sessions and where required individual virtual or face to face appointments.
- Support is currently being provided to people with long COVID via services already established in the community ,depending on their symptoms. For example, this may include General practice, primary care services, rehabilitation services, the Centre for Integrative Care and specialist clinical services such as cardiology and respiratory medicine.
- The Board has a dedicated resource to support staff with long COVID to remain in or return to work.

## NHS Highland, £119,641

- Development of a multi-disciplinary complex review group to help signpost and coordinate care for those patients who are severely impacted by long COVID and struggling to recover with rehab.
- The Board already has an operational long COVID pathway, including occupational therapy and physiotherapy staffing to support assessment, goal setting, rehabilitation and coordination for people with long COVID. The pathway will signpost to self management resources as a first option and can be stepped up to supported self management including one to one or group support.
- Close working with third sector colleagues, 'Let's Get on with it Together', in self management resources, groups and peer support. The team is a board wide virtual team offering remote support by telephone or NHS Near Me (video appointments). The team will be working closely with local services across the wide geographical board area to enhance local support.

## NHS Lanarkshire, £320,007

- Delivery of a single access point to a long COVID rehabilitation pathway, supported by a team of occupational therapy, psychology, physiotherapy, dietetics and speech & language therapy. The team can assess and help with physical, mental or social difficulties people may have that are related to long COVID.
- The funding made available through the long COVID Support Fund is contributing towards paying for the multi-disciplinary staff supporting the pathway.
- It will support the implementation of a digital, app based tool that allows people with long COVID to measure and monitor their symptoms. This information supports the assessment, intervention and evaluation of their care.

## NHS Lothian, £372,215

- Staged scale-up of the long COVID supported Self Management Pathway including the digital self management tool and Chest, Heart & Stroke Scotland advice line. Learning from each phase of the pathway will inform the next stage to implement the pathway across NHS Lothian and its partnership areas of East Lothian, West Lothian, Midlothian, and the City of Edinburgh.
- The application of existing data including how many people have received a clinical intervention and the routes taken to access these services, to inform the development of the Lothian model for long COVID services.

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- At present, existing NHS Lothian and associated Health and Social Care Partnership services are providing clinical support for people who need intervention to help them manage their symptoms. People with long COVID have access to a wide range of services including respiratory, neurology, rheumatology and musculo-skeletal teams, amongst others.
- In addition, a trial group of GP Practices across Lothian can refer through to the 'Tailored Talks' digital self management platform, providing access to tailored health information to help them to manage their symptoms and a 12-week programme of support from Chest, Heart & Stroke Scotland's advice line.

## NHS Orkney, £14,716

• Support for a specialised physiotherapist who assesses and supports long COVID cases as a significant part of their job plan. This is in addition to support being provided via services already established in the community depending on people's specific symptoms.

## NHS Shetland, £13,676

• Facilitation of a local pilot to examine whether the the implementation of an Allied Health Professional Care-Coordinator role improves outcomes for people living with long COVID.

## NHS Tayside, £194,620

- Enhancement of the Tayside long COVID rehabilitation pathway. This pathway will be accessed via an individual's GP in line with SIGN guidelines to deliver an accessible point of access for assessment, support and co-ordination.
- At present, people can be supported by national NHS Inform self management and the Chest, Heart & Stroke Scotland advice line as well as local services already established across within the community depending on their symptoms. People can also access the community listening service for support.
- Where required, services such as psychology, secondary care teams and local specialist rehabilitation teams, embedded within local communities (including physiotherapy, occupational therapy, psychology, dietetics and speech & language therapy) can be accessed via GPs, depending on what is most appropriate for a person's needs.

## NHS Western Isles, £19,988

- Facilitation of Public Health intelligence activity to establish the incidence and need related to long COVID across the Western Isles.
- At present, support for people with long COVID is accessible via general practice, with multiple options available for onward referral in line with individual clinical need.

## Thistle Foundation, £87,343

• Delivery of a 'Good Conversations' training programme for Allied Healthcare Professionals in Scotland.

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## NHS National Services Scotland, £370,000

- A total of £370,000 has been identified to support NHS National Services Scotland to undertake national level actions to improve care and support for people with long COVID.
- This includes the operation of a National Strategic Network for long COVID, and the once-for-Scotland procurement of a digital tool to assist the screening and evaluation of care for people with long COVID.

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