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Bhoireannach
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16 June 2023

Dear Jim,

Report of inquiry on long COVID

I want to thank the COVID-19 Recovery Committee for the work it has undertaken as part of its inquiry focussing on awareness and recognition, therapy and rehabilitation, and study and research in relation to long COVID.

I note that the Committee received a wealth of information from academics, healthcare practitioners and most importantly those with lived experience of this condition. It is clear from the Committee's comprehensive report that this evidence proved to be informative and insightful.

I welcome the opportunity to respond to the recommendations outlined in the Committee's report. These responses can be found in Annex A to this letter, and I hope that the Committee finds this information useful.

Tha Ministearan na h-Alba, an luchd-comhairleachaidh sònraichte agus an Rùnaire Maireannach fo chumhachan Achd Coiteachaidh (Alba) 2016. Faicibh www.lobbying.scot

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Please do not hesitate to get in touch if you require any further information.

Regards,

Jenni Minto MSP

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Recommendation (incl paragraph number in report)	Response
Awareness and recognition	
<p><i>35. The Committee was concerned to hear of the apparent lack of any lessons being learned from other chronic illnesses such as Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) in raising awareness of Long COVID and avoiding stigma around the condition, and would ask the Scottish Government whether it has any plans to look at this given the evidence the Committee has heard.</i></p>	<p>The Scottish Government has made a clear public recognition¹ of the stigma and disbelief that many people with ME/Chronic Fatigue Syndrome have felt from those who do not understand their condition. As a consequence, the Scottish Government is progressing a range of activity to support the implementation of an updated clinical guideline² for the diagnosis and management of the condition.</p> <p>Supporting the implementation of relevant clinical guidance is also an area of focus for long COVID, and officials in respective policy teams are liaising to share insights on stakeholder communications from these related activities as appropriate.</p>
<p><i>46. The Committee notes the overwhelming evidence that there is a lack of awareness of Long COVID among the general public and that it is important that the Scottish Government acknowledges the evidence received throughout this inquiry.</i></p>	<p>To assess the level of awareness of long COVID among the general public, we commissioned the market research and data analytics company YouGov to include questions related to long COVID within a polling exercise conducted during the week beginning 21 February 2023. The total sample size for the poll was 1,001 adults and the figures were weighted and representative of all Scottish adults (aged 18+).</p> <p>The polling results demonstrated that the level of awareness of long COVID was high, finding that:</p> <ul style="list-style-type: none"> ○ 94% of people had heard of long COVID

¹ https://www.parliament.scot/chamber-and-committees/official-report/search-what-was-said-in-parliament/meeting-of-parliament-02-02-2023?meeting=14128&iob=127991#orscontributions_M5669E393P730C2464013

² [Overview | Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management | Guidance | NICE](#)

56. The Committee notes the Scottish Government's £40,000 funding announced in September 2021 to deliver a targeted Long COVID marketing campaign in primary care settings and community pharmacies and its Long COVID Awareness Campaign. However, given the concerning evidence heard by the Committee of the lack of awareness and recognition of Long COVID and the impact this has had on individuals, the Committee considers a public health campaign is needed to address this.

- 76% of people agreed with the statement that long COVID is a serious condition for those that experience it.

We will continue to consider future opportunities to monitor awareness levels of long COVID and its impact.

We note the Committee's finding that "a majority of individual respondents reported not being taken seriously by friends and colleagues who consider that Long COVID is a 'made up' illness" and recognise the negative impact that this will have had on their health and wellbeing.

We are working with people living with long COVID, and healthcare professionals supporting them, to develop case study videos for the NHS inform long COVID microsite providing insight into long COVID and people's experiences of living with the condition. Recruitment of participants for the videos was conducted through communicating the opportunity to relevant stakeholder organisations, which included Long Covid Scotland. We will consider opportunities to maximise the reach and impact of the case study videos, including working with stakeholder organisations and the long COVID Strategic Network.

The case study videos form part of a wider programme of content updates to further develop the information available on the NHS inform long COVID microsite. These improvements have been informed by user experience research with people living with long COVID, and will include advice informed by people living with long COVID on how to speak to people about the condition and its impact on their lives. A stakeholder communications toolkit will be developed and disseminated in Autumn 2023 to support the communication of these updates and developments to the NHS inform long COVID microsite content.

In addition, as outlined in further detail in response to point 57, in the financial year 2022-23, we provided funding of £10,000 to Covid Aid to undertake a project aiming to increase awareness of long COVID among the Scottish population, by signposting to information about long COVID and the types of support available.

<p><i>57. The Committee welcomes the additional £10,000 funding for the delivery of Long COVID advertising and signposting activity and recommends that the Scottish Government speaks directly to those with lived and living experience, including Long Covid Scotland, to help inform its future public health campaign activity. In addition, the Committee requests that the Scottish Government provides further clarity on how this funding will be spent.</i></p>	<p>As outlined in the response to point 56, we are working with people living with long COVID to develop case study videos which help illustrate people’s experiences of living with long COVID and its impact on their lives. Recruitment of participants for the videos was conducted through communicating the opportunity to relevant stakeholder organisations, which included Long Covid Scotland.</p> <p>In the financial year 2022-23, we provided funding of £10,000 to Covid Aid to undertake a project aiming to increase awareness of long COVID among the Scottish population, by signposting to information about long COVID and the types of support available.</p> <p>The grant enabled Covid Aid to fund eight weeks³ of paid advertising. The advertising campaign was an extension of the charity’s ‘longest ad’⁴ campaign, which was informed by the stories of people with long COVID who had accessed Covid Aid’s support services. The advertising was present across online search tools and social media. The aim of this advertising campaign was to reach tens of thousands of people across Scotland.</p> <p>Covid Aid utilised £3,000 of the grant to pay for staffing resource to action this project and used the remaining £7,000 for paid advertising.</p> <p>At the half-way point of the 8 week campaign, Covid Aid reported that the campaign had reached over 1 million unique users which had exceeded their target with the remainder of the campaign still to go. This equated to a spend of around £3 per 1,000 users. In addition, the charity reported over 250 members joining its’ Scotland specific support community.</p> <p>Covid Aid initiated a ‘test period’ for the different creatives, to inform the optimisation of the adverts going forward. Feedback was captured by Covid Aid at the half-way point of the campaign from social media sites. The charity reported that comments had been made by users expressing that they had related to the content within the adverts.</p>
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³ 29 March – 3 June 2023

⁴ [‘The Longest Ad’ released to highlight plight of 2 million in UK with Long Covid | covid:aid \(covidaidcharity.org\)](https://www.covidaidcharity.org/)

<p><i>68. The Committee welcomes the comments from the then Cabinet Secretary regarding the Covid Sense campaign and publicising the current booster vaccination programme. The Committee recommends the Scottish Government reviews its current publicity strategy for the booster vaccination programme to ensure its effectiveness in raising awareness of the programme and reducing apathy around booster vaccinations.</i></p>	<p>We regularly review our approach to communications activity. For example, upon completion of the winter vaccination campaign “Don’t let your protection fade”, independent evaluation was undertaken to assess the reach, impact, effectiveness and actions taken by the target audience as a result of the marketing activity. The campaign reached 88% of the adult population who saw or heard campaign messages on average 17.5 times.</p> <p>The findings from the evaluation highlighted that there was good spontaneous awareness of the Winter vaccination campaign with 54% of the target audience recalling advertising or publicity on the topic and the campaign drove practical action among recognisers with almost two thirds (63%) taking action. The key campaign messages were successfully communicated with the main message take-out focused on the importance/benefits of the flu vaccination at 73% and/or encouragement to get the vaccine at 62%.</p> <p>These findings will be combined with uptake data and lessons from approaches taken elsewhere in the United Kingdom to inform the development of communications activity during Quarter 4 of 2023 to promote the COVID-19 vaccine uptake among eligible cohorts. This will consider raising awareness of the autumn/winter programme as well as reaching those more vaccine hesitant audiences.</p>
<p><i>112. The Committee recommends the Scottish Government works with the National Strategic Network and NHS Education for Scotland as a matter of urgency to develop and implement its education strategy in relation to the awareness and recognition of Long COVID within the medical profession. This work should consider the evidence heard by this committee in relation to—</i></p>	<p>The Strategic Network has developed a draft education strategy following consultation with people living with long COVID and those responsible for planning and delivering healthcare services. The strategy will be put to the Steering Group and Strategic Oversight Board of the Strategic Network for consideration and sign-off.</p> <p>Aligned with the draft strategy, the Strategic Network is already actively implementing a range of activity to support the information and learning needs of healthcare professionals working to support people living with long COVID. For example;</p> <ul style="list-style-type: none"> • The Network is working with Public Health Scotland to disseminate regular bulletins providing a summary of recent relevant research and evidence on long COVID. The Committee heard positive feedback regarding these bulletins and their value to those planning and delivering services during its evidence session on 23 February 2023.

- *allowing time for GPs to undertake CPD on Long COVID;*
- *learning from medical professionals such as Dr Claire Taylor who have developed expertise in Long COVID;*
- *sharing best practice among health professionals;*
- *involving people with lived and living experience in a meaningful way; and*
- *harnessing existing informal networks both in Scotland, across the UK and internationally.*

- The Network has implemented a programme of Peer Network sessions, providing education on topics suggested by members and the opportunity to seek support from peers and share good practice. Three sessions have been facilitated to date, including focus on chronic pain management and dysfunctional breathing.
- The Network has facilitated two information sharing sessions with researchers leading Chief Scientist Office (CSO) funded research on long COVID, to enable them to engage with NHS colleagues across Scotland who are developing and delivering support and services for people with long COVID. This has two important functions:
 - To make NHS colleagues aware of relevant emerging findings from research studies, which may inform their approach to providing care and support for their patients with long COVID.
 - To make NHS colleagues aware of relevant research opportunities that they can signpost or facilitate access for their patients to. And to give researchers access to local networks to help communicate about, and recruit participants to any current and future studies.
- The Network has facilitated practice sharing events with those delivering support for people living with long COVID elsewhere in the UK. This has included a presentation and Q&A session from Leeds Community Healthcare NHS Trust's Long COVID Community Rehabilitation Service team.

The Strategic Network has appointed a Lead Clinician, Dr Camilla Milne, and is engaging with a range of clinical stakeholders and stakeholder organisations to raise awareness of the Network and its outputs, including NHS Education for Scotland, and the Royal College of General Practitioners.

In December 2022 at the Scottish Local Medical Committee conference, the former Cabinet Secretary for Health and Social Care, Humza Yousaf MSP announced that the Scottish Government would support Health Boards to resume Protected Learning Time for GP practices. A task and finish group was established to determine how Health Boards should best provide practices with Protected Learning Time and the Scottish Government has announced funding of £500,000 will be added to the Primary Medical Services (Revenue) Allocation later this year to support.

<p><i>124. The Committee notes however the difficulties described by respondents to the call for views in accessing disability support which can be exacerbated given common symptoms of Long COVID such as brain fog and fatigue. The Committee recommends that the Scottish Government works with the relevant social security agencies to identify means to make the applications process more accessible and any additional support which would help individuals with Long COVID when applying for disability benefits, such as Carers Allowance and PIP.</i></p>	<p>Social security is a human right and the Scottish Government is making sure that everyone gets the financial support they are entitled to, putting dignity, fairness and respect at the heart of social security in Scotland.</p> <p>Child Disability Payment was rolled out in November 2021. Adult Disability Payment began receiving applications as part of a pilot from 21 March 2022. This was followed by a national rollout beginning on 29 August 2022. These benefits are administered by Social Security Scotland on behalf of the Scottish Government.</p> <p>The application process for Child Disability Payment and Adult Disability Payment has been designed with disabled people to ensure it is as clear and straightforward as possible. We always start from a position of trust.</p> <p>Social Security Scotland's Local Delivery service provides in-person support, with staff located across the country. Local delivery staff can help people experiencing brain fog or fatigue by assisting them to complete paper, telephone or online application forms. They can provide this support to people at a location and time that suits them within their local area.</p> <p>A person-centred approach to deciding who is entitled to disability assistance is one of the cornerstones of our social security system. We provide clear and accessible guidance to clients so that they understand what information the Agency needs to make a decision about their entitlement.</p> <p>The way entitlement decisions are made for Adult Disability Payment is very different from Personal Independence Payment. Our intention is to get decisions right first time by trusting what people tell us and the information available. Social Security Scotland proactively gather information that could support a person's application, reducing the burden on the person. We will not carry out any face-to-face assessments like those carried out by the Department for Work and Pensions (DWP).</p>
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	<p>We have heard from families about the important difference that Child Disability Payment can make by helping with the extra costs of caring for a disabled child. The benefit is non means-tested, non-taxed, will rise with inflation and is a passport to other types of support, such as a Blue Badge, Housing Benefit, Carer’s Allowance, Child Tax Credit, Universal Credit and exemption from the benefit cap.</p> <p>A large proportion of respondents to the Child Disability Payment Client Survey 2022⁵ were supportive of the application process, with 85% of respondents agreeing or strongly agreeing that ‘the application process enabled them to fully explain their child’s care and mobility needs’ and nearly 90% felt ‘they were treated fairly and respectfully throughout the application process’. Additionally, over 80% of people told us that Child Disability Payment helped make a difference to their life.</p>
<p>Therapy and rehabilitation</p>	<p>The Scottish Government notes that NHS National Services Scotland provided written evidence to the Committee on 10 February regarding the activity of the National Strategic Network. A representative of NHS National Services Scotland and the Chair of the Strategic Network’s Strategic Oversight Board gave oral evidence to the Committee on 23 February to answer questions posed by members.</p> <p>I wrote to NHS National Services Scotland on 16 June 2023 regarding the activity of the National Strategic Network. This correspondence welcomed a range of actions underway by the Network’s programme team to enhance the transparency and visibility of the Network’s activity, including;</p> <ul style="list-style-type: none"> • The development and implementation of a communications strategy, to guide the Network’s communication with internal and external stakeholders within an interest in the Network’s activity • The development and publication of an annual report, summarising the key activities of the Network across 2022-23

⁵ [Child Disability Payment Client Survey 2022](#)

<p><i>visibility of its meetings, priorities, and outputs. The Committee also requests that the Scottish Government provides an update to the Committee on actions taken to date by the National Strategic Network to improve coordination and consistency of access to services across Scotland over the next six months.</i></p>	<ul style="list-style-type: none"> • The development and sharing of highlight reports to ensure that Network stakeholders are kept abreast of progress and to support communications between the constituent groups of the Network <p>In addition, the letter requested that;</p> <ul style="list-style-type: none"> • Contact details for the Strategic Network programme team were added to the NHS National Services Scotland Strategic Networks web page, in line with other Strategic Networks • Meeting minutes and key programme documentation were made available on the NHS National Services Scotland website, or other dedicated web presence as appropriate • The Strategic Network programme team facilitate an opportunity for the Minister for Public Health and Women’s Health to meet with the Network’s Lived Experience group to understand its current priorities and activities. <p>The Scottish Government has requested that NHS National Services Scotland provides the Committee with a copy of the Strategic Network’s annual report for 2022-23.</p>
<p><i>173. The Committee notes the evidence on the need for Long COVID clinical pathways across all health boards and is disappointed to hear that, to date, only six health boards have these in place and two more were aiming to have them in place by the end of March 2023. The Committee recommends that the Scottish Government works with National Strategic Network on implementing Long COVID pathways across all territorial health boards in Scotland</i></p>	<p>The former Cabinet Secretary for Health and Social Care wrote to all territorial NHS Boards in October 2022 to highlight that delivering improved care and support for people living with long COVID is a priority for the Scottish Government, and outlined an expectation that Boards take urgent action to recruit to, and deliver their proposed models of care for which funding was allocated. While the Scottish Government’s role is to set the strategic policy for the NHS in Scotland, NHS Boards and healthcare professionals locally have responsibility for both service delivery and people’s care.</p> <p>At present, 9 Boards have long COVID pathways in operation, and 5 remain in development. In NHS Boards where these pathways are in the process of development, people with long COVID can receive assessment and input from existing services, based on their symptoms and needs.</p>

<p><i>and the development of standardised guidance. The Committee requests that the Scottish Government provides the Committee with indicative timescales for implementing these priorities.</i></p>	<p>The Strategic Network has implemented a clear governance structure, which includes a Service Planning Group consisting of Service Planners from each territorial NHS Scotland Boards, who are responsible for the local development and implementation of long COVID pathways at NHS Board level. The Scottish Government and Strategic Network will continue to seek regular updates from NHS Boards on progress via this group, and would be happy to share an update with the Committee following the Service Planning Group's next meeting in July. In addition, we will continue to use the forum provided by the Service Planning Group to identify where any additional support may be required at a national level to support NHS Boards.</p> <p>The national clinical guideline for long 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 includes not only recommendations and guidance on the clinical management of those with long COVID, but recommendations for those planning services.</p> <p>In addition, the long COVID Strategic Network's Clinical and Subject Matter Expert Group, is collating information on existing pathways of care and is supporting the development of standardised guidance in specific thematic areas where identified as appropriate. For example, the group has developed guidance on a pathway for the management of Postural Orthostatic Tachycardia Syndrome (PoTS) which it is anticipated will be finalised and disseminated to NHS Boards in July.</p>
<p><i>180. The Committee considers a single point of contact for patients to access services and coordinated support would be helpful. The Committee recommends that the Scottish Government and the National Strategic Network works with health boards to introduce a single</i></p>	<p>We know that for some people living with long COVID, interacting with different systems and services can be challenging. We recognise that there is a benefit in providing continuity of care with the same healthcare professional or team as much as possible.</p> <p>The Scottish Government is providing funding to support NHS Boards to increase the capacity of existing services providing support to people with long COVID, develop these in to more clearly defined pathways and to provide a more co-ordinated experience for those accessing support.</p>

<p><i>point of contact for each Long COVID patient across all territorial health boards in Scotland.</i></p>	<p>The individual delivery models being utilised and progressed by NHS Boards will vary, as they are tailored to local circumstances and needs. For example, some NHS Boards have developed single points of access for assessment and co-ordinated support from services including physiotherapy and occupational therapy. In other areas, the co-ordination role will be fulfilled by the primary care team based in the person’s local GP surgery.</p> <p>The Strategic Network is taking forward a dedicated workstream to agree the outcomes, indicators, monitoring and evaluation that will be collected and used to accelerate progress on and inform the planning and delivery of services. These metrics are being agreed on a ‘once-for-Scotland’ basis, which will provide a consistent set of measures that can be used to benchmark and compare different models of service delivery, and their outcomes. This information will reviewed to enable us to adapt our approach informed by the evolving evidence base.</p>
<p><i>194. The Committee notes the workforce and capacity pressures faced by health boards across Scotland and the impact this is having on Long COVID service development. The Committee further notes the recruitment difficulties faced by health boards due to the non-recurring nature of funded posts and other pressures is resulting in health boards not using all of the budget allocated to them. Whilst reallocating the underspend in health board funding will assist with self-</i></p>	<p>The Scottish Government wrote to NHS Boards on 10 May 2023 to confirm their 2023-24 allocations from the long COVID Support Fund. A total of £3 million is being made available from the fund over 2023-24. In addition, the letter provided an update regarding indicative*⁶ funding for the financial year 2024-25, and confirmed that any funding not utilised by NHS Boards within the financial year 2022-23 will be made available to Boards in the financial year 2025-26.</p> <p>We engage with NHS Boards on a regular basis regarding their capacity needs, and will continue to do so in order to inform the allocation of the long COVID Support Fund. Going forward, we will consider baselining long COVID Support funding for NHS Boards at a level to be determined based on progress made by NHS Boards over 2023-24.</p>

⁶ *As with all our financial planning for future years, budgets are subject to final agreement through the annual budget process. The allocation for 2024-25 is therefore subject to the Scottish Parliament’s approval of the Scottish budget.

<p><i>management of some patients where appropriate, it is really symptomatic of the current funding arrangement for Long COVID clinical services being not sustainable. The Committee urges the Scottish Government to work with health boards to rethink its approach to funding Long COVID services as a matter of urgency.</i></p>	
<p><i>213. The Committee notes the differing views on the use of Long COVID clinics and can see both advantages and disadvantages to that approach. The Committee notes the then Cabinet Secretary's comments that he had never been opposed to Long COVID clinics in principle but wants to support health boards to design services that meet their local needs. The Committee invites the Scottish Government, working with the National Strategic Network, to take a leadership role in reviewing the best practice of Long COVID clinics and evaluate whether they may be an appropriate development here. The Committee considers it essential that, whatever approach is adopted by health boards, it must be a</i></p>	<p>The rationale in the clinical guideline developed by SIGN, NICE and the RCGP regarding services planning 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 a consequence, rather than mandating one model, the Scottish Government’s approach is to support NHS Boards to develop and deliver the models of care most appropriate for their local needs.</p> <p>As outlined in the response to point 180, the Strategic Network is agreeing a consistent national set of measures that can be used to benchmark and compare different models of service delivery being utilised by NHS Boards, and their outcomes. In addition, we have requested with NHS National Services Scotland that an evaluation of post COVID services (including long COVID clinics) in comparison to pathways in place in Scotland be included within the Strategic Network’s workplan for 2023-24.</p> <p>It is intended that the information and data from these evaluation processes will be made available to NHS Boards to inform the further development and delivery of services. Going forward, we will consider baselining long COVID Support funding for NHS Boards at a level to be determined based on progress made by NHS Boards over 2023-24.</p>

<p><i>holistic approach to Long COVID services, supported by a clear referral pathway that includes access to multidisciplinary teams of specialists.</i></p>	
<p><i>226. The Committee recommends that the Scottish Government works with National Strategic Network to progress the workstream on children and young people as a matter of urgency and involves Long Covid Scotland and Long Covid Kids in this work, which should include milestones and timescales for action. The Committee also requests to be kept updated on this work.</i></p>	<p>The Strategic Network's Children and Young People Group has been established and met for the first time on 17 April 2023. The group's membership includes lived experience representatives from Long Covid Scotland and Long Covid Kids. The group will continue to meet as part of the overall governance structure of the network, and the publication of a pathway for children and young people is in the network delivery plan for September 2023.</p>
<p>239. The Committee notes the evidence it received on what is working well across the UK and the differing approaches to self-referral. The Committee recommends that the Scottish Government and National Strategic Network review the evidence heard by this Committee to identify areas of best practice and opportunities for shared learning and to ensure that clinical pathways and NHS services in Scotland reflects this.</p>	<p>The report of the Committee's inquiry has been shared with members of the Strategic Network's Service Planning Group.</p> <p>The Strategic Network will continue to facilitate the sharing of learning and practice through the delivery of educational sessions. As highlighted in the response to point 112, these have included engagement with those delivering support for people living with long COVID elsewhere in the UK.</p>

Study and research	
<p><i>268. Given the importance of ongoing research into Long COVID on service development and treatment of the condition, the Committee encourages the CSO to continue its work in ensuring that Scottish clinicians, scientists and public health researchers get optimal access to UK funding for Long COVID research. In addition, the Committee recommends that the Scottish Government considers funding further research through CSO on areas outlined in this report.</i></p>	<p>The Chief Scientist Office (CSO) will continue to work with UK health research funders in order that funding opportunities for research on long COVID are open to the research community in Scotland. In addition, CSO's competitive applied health research grant and fellowship schemes are open to applications for research on long COVID, including in areas identified in the Committee's report. Applications submitted to these schemes are subject to independent expert peer-review with funding recommendations made by independent expert committees.</p> <p>Recently, through this process, funding was awarded⁷ by CSO for a new research project to examine, and explore how to improve, support through primary care for those with long COVID. CSO investment, through NHS Research Scotland, in clinical research infrastructure will also continue to support studies and trials across clinical areas, which can include studies and trials on long COVID.</p>
<p><i>277. The Committee welcomes the work done by (sic) National Strategic Network to facilitate a consistent national approach to the collection of data relating to Long COVID, however the Committee considers that progress in this area needs to be accelerated. The Committee requests that the Scottish Government works with the National Strategic Network to progress this work on agreeing data collection outcomes, indicators, monitoring and</i></p>	<p>A project delivery plan with a schedule of activities is in the final stages of development.</p> <p>Using a theory-based model of change, a framework to evaluate the activities, outputs and outcomes achieved by the network has now been developed. This has been developed in collaboration with all of the Strategic Network's constituent groups. The framework will articulate key milestones for delivery against key activities of the network, including service delivery.</p> <p>In addition, the Strategic Network is establishing a minimum national dataset for services to collect, to support the monitoring and evaluation of the delivery of services at a national level. This dataset will include a selection of patient related outcome measures (PROMs) identified through consultation with members of the Strategic Network and informed by academic input regarding validated tools and lessons learned from the LOCOMOTION study with the University of Leeds, which is evaluating 10 long COVID services across the</p>

⁷ [Health Improvement, Protection and Services Research Committee 2022 – Chief Scientist Office \(scot.nhs.uk\)](https://www.scot.nhs.uk/health-improvement-protection-and-services-research-committee-2022/)

<p><i>evaluation both locally and nationally and keeps the Committee updated on this work.</i></p>	<p>UK. The implementation of the C-19 YRS digital assessment and monitoring tool⁸ will facilitate the collection of this minimum dataset.</p>
<p><i>288. The Committee notes the calls for more data on the prevalence of Long COVID and the impact that incorrect coding of Long COVID can have on the accuracy of prevalence data. The Committee recommends that the Scottish Government works with the National Strategic Network and health boards on improving accurate coding of Long COVID by GPs and explores possible simplifications to the process of coding. The Committee requests that it is kept updated on this work.</i></p>	<p>Our long COVID Implementation Support Note⁹ accompanies the clinical guideline which was developed by the Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners. It has been developed with input from clinicians across a range of disciplines and includes instruction on the appropriate codes for use within the ‘Vision’ and ‘EMIS PCS’ primary care information systems. The Chief Medical Officer for Scotland wrote to all NHS Boards¹⁰ in February 2022 to highlight the Implementation Support Note and encourage its use by clinicians.</p> <p>We are working with NHS National Services Scotland Digital and Security to deliver improvements to the search keywords which may be used within the Vision platform to locate the appropriate codes for Ongoing symptomatic COVID-19 and Post-COVID-19 Syndrome. It is anticipated that these updates will be deployed in the next dictionary release, which is expected to be released by the software provider in July 2023. Existing guidance for clinicians will be updated and communicated to reflect changes as appropriate.</p>
<p><i>296. The Committee notes the importance of data sharing across NHS IT systems in planning services and the barriers faced regarding data protection issues. The Committee requests that the</i></p>	<p>Scotland’s first Data Strategy for health and social care¹¹ was published on 22 February and was accompanied by a public facing executive summary¹². The strategy will take an iterative approach to ensure that it is developed in a meaningful way and can articulate short term deliverables whilst being regularly updated to reflect real-world changes.</p>

⁸ [Home - C19-YRS](#)

⁹ [Managing the long-term effects of COVID-19 \(sign.ac.uk\)](#)

¹⁰ [Chief Medical Officer and Secretariat Division dot \(scot.nhs.uk\)](#)

¹¹ [Data Strategy for health and social care](#)

¹² <https://www.gov.scot/isbn/9781805255147>

<p><i>Scottish Government keeps the Committee updated on its work in this area and on the delivery of its priorities of the Health and Social Care: Data Strategy.</i></p>	<p>We intend to produce updates on the progress of deliverables to both professional stakeholders and the public, and would be happy to update the Committee at its convenience.</p>
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