**Long Covid Stakeholder Statement**

**Joint call to ensure that Scotland’s Long Covid Strategy is co-produced and values lived experience.**

We welcome that the Scottish Parliament is having a national discussion about the experiences of people with Long Covid and seeking to consider what action is required to enable people to achieve a better quality of life. We call on the Scottish Government and Scottish Parliament to ensure that people with lived experience are at the centre of policy, practice, and decision-making in developing services and supporting people with Long Covid. We also highlight the need for decision-makers to value, involve, and embed the expertise of the third and independent sectors.

The NHS and Long Covid research communities have provided a range of support for people with Long Covid – but they cannot, and should not, operate in a vacuum. Education, social security, healthcare, social care, and a range of areas of policy and public life must be enabled to support people with Long Covid, and their families. The value of embedding lived experience in decision-making is long-established and evidenced in research. In order to meaningfully co-produce a strategy that will work for people with Long Covid, all areas of health and social care, and connected policy areas, should be informed by the voices of lived experience.

If we take the opportunity to fully embed lived experience in policy and practice, the gains will be considerable. More effective treatment pathways and support for people living with Long Covid will ensure better use of resources and a better quality of life for those people. We must acknowledge and value expertise by experience, and deliver clinical and social support to make this happen.

We call on the Scottish Government to ensure that they:

* Include the voices of adults, children and young people with Long Covid from the earliest stages of strategic planning and decision-making, following a “nothing about us without us” policy throughout.
* Provide clear feedback loops on how lived experience will be used, by whom, and when, and report how it has impacted decision making at a local and national level. People with lived experience of Long Covid should be involved in the design, delivery, and implementation of any review of services
* Design communications to ensure that they are fully accessible for people living with Long Covid.
* Ensure that people living with Long Covid have equal access to clinical interventions, supported self management, and social support, no matter where they live in Scotland. The Scottish Government should facilitate health, social care, education, and social security professionals at a national level to share examples of best practice in supporting people with Long Covid. This sharing of good practice should include direct guidance from people with lived experience of Long Covid.
* Improve understanding and knowledge of Long Covid in the community. The Scottish Government should run ongoing national Long Covid communications campaigns to educate the public about Long Covid and the effects it can have on people, and highlight resources and supports. Key themes should include supportive employment practices, information about social security and social care, and educational best practice.
* Improve training to empower a range of professionals to better support people with Long Covid. The Scottish Government, Health Boards, Health and Social Care Partnerships and local authorities should invest in and facilitate essential training for health, social care, education, and social security professionals to improve understanding of Long Covid and its implications so that people experience an “any door” approach to support. This training should take a trauma-informed approach and be developed and delivered in conjunction with those with lived experience.

The signatories to this statement are happy to provide assistance in embedding lived experience. Regarding communication, we recommend that accessible communication should include the following:

* All material should be shared well in advance of any meetings, including agendas with suggested timings (to enable processing time and pacing).
* All material should be written in plain and concise English (with other accessible formats available if required).
* Advance notice should be given for any meetings or deadlines, to allow pacing and the balance of care responsibilities.
* Key information should be shared with all stakeholders; people with lived experience should not be given redacted material relative to health and social care professionals (except where there are issues of anonymity, etc.).
* Regular breaks should be timetabled into meetings, to allow people to pace themselves.
* Organisers should ensure that there are equal opportunities in each meeting or discussion for effective communication from each group of stakeholders.
* The Scottish Government should provide clarity on who is providing input on Scotland’s Long Covid Strategy, and how the different groups are connected, including detail on the governance, structure, and accountability systems.

**Signatories:**

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