

The Health and Social Care Alliance Scotland (the ALLIANCE)

Accessing Long Covid services in Scotland: to be believed, listened to, and supported



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

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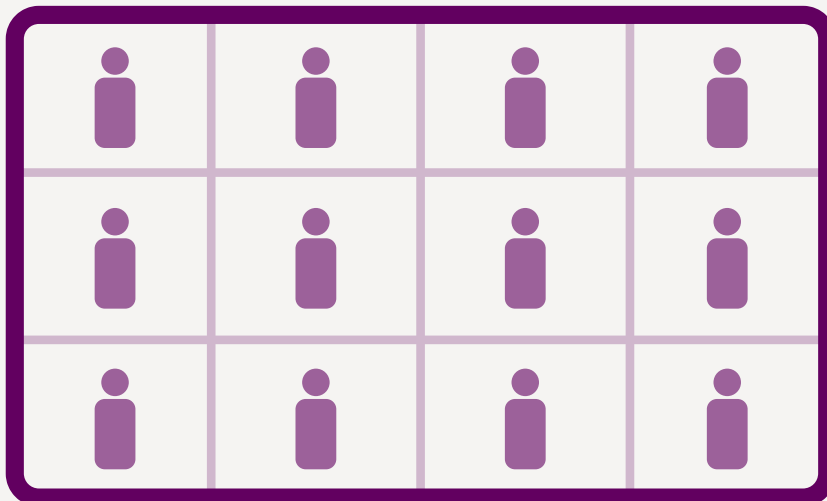
Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) have established a lived experience network for people affected by Long Covid, to gather a wide range of feedback to inform the design and development of Long Covid service delivery across Scotland.

This network works closely with the Scottish Government and NHS National Services Scotland on implementation of the Long Term Effects of COVID-19 Strategic Framework and is directly linked to the working groups developing and influencing the design and development of Long Covid services in Scotland.

The ALLIANCE's Lived Experience Network were approached by NHS National Services Scotland (NSS) to engage with people with experience of Long Covid around why people in Scotland are disengaging from Long Covid services.

The following report summarises the learning from this engagement, which was conducted through an online survey and two online focus groups, throughout November and December 2023. There were a total of 210 people taking part. This report considers the evidence gathered through the survey and focus groups, highlighting trends and experiences of people affected by Long Covid into how they access services, and why they may have disengaged from services.



Methodology

For engagement around the topic of accessing and disengaging with services, a flexible approach was taken, to allow for individuals to participate at their own pace. By offering both a survey with a flexible time limit and two online focus groups, we were able to cater to more communication preferences and needs. The option to leave and return to the survey allowed respondents to answer the questions at a speed that suited them. Similarly, by opting for online focus groups, at different dates and times, a level of flexibility and geographic inclusion was ensured to accommodate the needs of the respondents.

Within the report, the survey findings and discussion from the focus groups has been combined to draw out themes which are informed by both engagement methods. Findings from the focus groups have been combined to draw out themes which are informed by both engagement methods. However, it must be noted when referring to statistics, these are representative of the survey responses only. However, focus group attendees may also have responded to the survey and therefore be captured in the statistics and/or comments. Due to anonymising the survey, no information around overlap was collected.



Experience of Long Covid

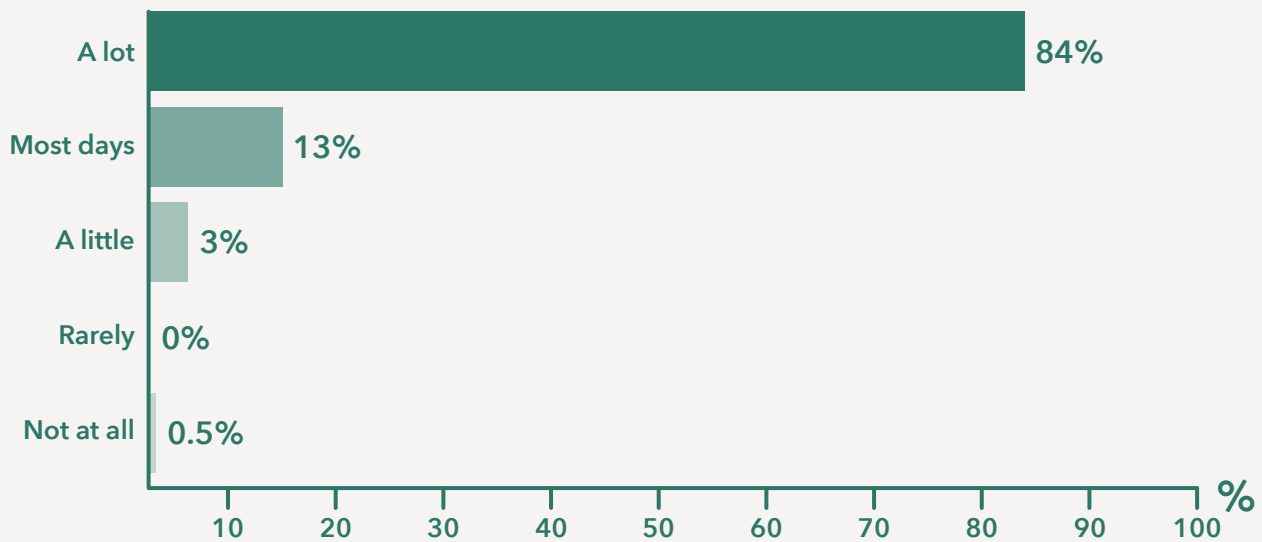
Around 45% of respondents specified that they had symptoms of Long Covid for over two years. There were 16% of respondents who chose “other”, each of these respondents provided further information to this question which all reflected those respondents had been living with Long Covid for around three years, or since the pandemic outbreak in 2020. 33% of respondents have had Long Covid for between one – two years, followed by 4% who have had Long Covid for six – twelve months.

From this information, it is inferred that 94% of the people responding to our survey have been living with Long Covid for at least one year, and 61% have had Long Covid for over two years.

This was similarly reflected in the focus groups, where majority of people have been living with Long Covid on a long term basis. The views shared through the focus group discussions and the survey are informed by people who have navigated the Long Covid services available in Scotland for a long period of time and will likely have experienced the changes and developments of those services.

When asked how much Long Covid has affected their daily lives, the respondents were offered to answer on a scale, from “a lot”, to “most days”, to “a little”, to “rarely”, and finally “not at all”.

How would you rate the effects of Long Covid on your, or the person you support's, wellbeing?



- 84% of respondents said that their Long Covid symptoms affect them “a lot”
- 13% are affected “most days”
- 3% are affected “a little”
- 0% are affected “rarely”
- 0.5% (one respondent) is affected “not at all”

In summary, over 96% of respondents are regularly affected by Long Covid. This was reflected in the comments and discussion with the focus group, where people detailed their experiences of Long Covid.

Many people shared that the impact of Long Covid is far reaching, *“Long covid has had a substantial negative impact on almost every aspect of my life”*, and especially affects tasks which require either mental or physical exertion. Many people detailed reducing hours at work, or being unable to work, as well as young people who can no longer attend school or university. The ripple effect of how this can go on to affect finances, relationships, and independence was widespread amongst the respondents.



It has affected every aspect of my life, I've lost my health, my job, my home, friendships and the life I used to live.

In terms of effects on health, a wide range of physical symptoms were mentioned including but not limited to breathlessness and respiratory conditions, fatigue, and PEM (post-exertional malaise), pain, insomnia, brain fog and PoTS (Postural orthostatic tachycardia syndrome). It is widely understood that long term conditions have a substantial adverse effect on mental health, and this appears to be the case with respondents, who, as established, have experienced these symptoms for a long period of time.¹ Many mentioned anxiety, depression, and low mood, as well as a feeling of grieving for the person they were before having Long Covid. It is important to note that not all these symptoms are recognised by name, but that comments and conversations around mental health have indicated this to be the case.



Some doctors have been rude and condescending towards me over the course of my illness, which has affected my mental wellbeing.

Out of the respondents, 88% had attempted to access some form of healthcare to support with their symptoms. In addition, respondents claimed that they had seen various GP's, consultants, and healthcare professionals, but not as part of a specific Long Covid service, due to the area they reside in and what is offered by that health board. Only 3% of respondents had not accessed any services for support with their Long Covid.

¹ Chris Naylor and others, Kings Fund. Long-term conditions and mental health The cost of co-morbidities. February 2012.

Available at [Long-term condition and mental health Chris Naylor February 2012 \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/long-term-condition-and-mental-health)

Services accessed

When asked what type of services they have accessed, there was a range of services highlighted by respondents with the services accessed reflecting the variety of symptoms related to Long Covid. This ranged from Cardiology and Respiratory services, as well as physiotherapy, CT scans, CBT (Cognitive Behavioral Therapy), ENT (Ear, Nose and Throat), Neurology and blood tests. 84% of respondents advised that the effects of Long Covid have impacted wellbeing, with many respondents accessing mental health services, often in short bursts of care and support.

According to comments shared within the survey, and the focus group discussions, Long Covid clinics were also used by respondents, where available. However, it was shared that many respondents did not feel that this was available in the area they live in. When respondents felt that NHS help was unavailable, they sought private health care services, which was a clear theme throughout the survey and focus group discussions.

Experience of accessing services

40% of survey respondents said their overall experience of accessing services was 'very', 'mostly' or 'a bit' positive, compared to 87.36% of survey respondents who said their experience was 'very', 'mostly' or 'a bit' negative. These questions were asked independently within the survey, to give space for respondents to reflect on both positive or negative experiences- in summary, however, the respondents typically had a more negative experience of accessing services. From the focus groups, most participants had both positive and negative experiences of accessing care, but this was very much based on individual relationships held with healthcare professionals, especially GPs. From the positive survey responses, it became very clear that the majority of respondents valued being listened to and believed. The most common answer regarding positive experiences was that they felt they were listened to by their GP, however, there was a sense that there is not a lot of help their GP can offer them, or services for them to be referred to.



I am listened to. But frustrating as GP can only offer so much.

Many respondents were very grateful to be referred to other services, such as respiratory specialists, as this gave them confidence through gaining information and knowledge about their symptoms, as well as the feeling that something was being done to help them.



Thorough examination of lungs and breathing, great explanation from consultant.

However, despite being seen by specialists this did not necessarily lead to treatment and help for their symptoms:



I have attended a few services where the people were very nice and sympathetic to my situation although still couldn't help treat my condition [...] I must stress though, that although the people made th[is] a positive experience, the lack of treatments they could offer was also negative.

With regards to the negative experiences respondents had when accessing services for Long Covid, there was a similar trend to the positive experiences. For example, some people found their GP to be understanding and helpful but there were many responses by people who had negative experiences with their GP. The term “gaslighting”² was frequently used. Respondents said that they felt their symptoms were dismissed by their GP, and there was limited understanding about the severity and impact of symptoms.



Being dismissed, ignored or being called a liar when discussing symptoms.

This was linked to what respondents saw as a lack of understanding and knowledge of Long Covid from healthcare professionals. Frequently respondents advised that GPs didn't know where to refer them and were unaware of any services that would help them.



No pathway for Long Covid, my GP doesn't know where to send me.

When referrals were put in place, the waiting times for responses and appointments was felt to be too long, and when the services are finally accessed, they were described as unsatisfactory. Respondents felt that they are often passed from one department to another and don't seem to get a treatment plan. Often, this leads to people accessing non-NHS services, and paying for private treatment.

²Young Scot. What is Gaslighting?. March 2021 [updated December 2022].

Available at [ThatsNotOK What Is Gaslighting? – Young Scot](#)



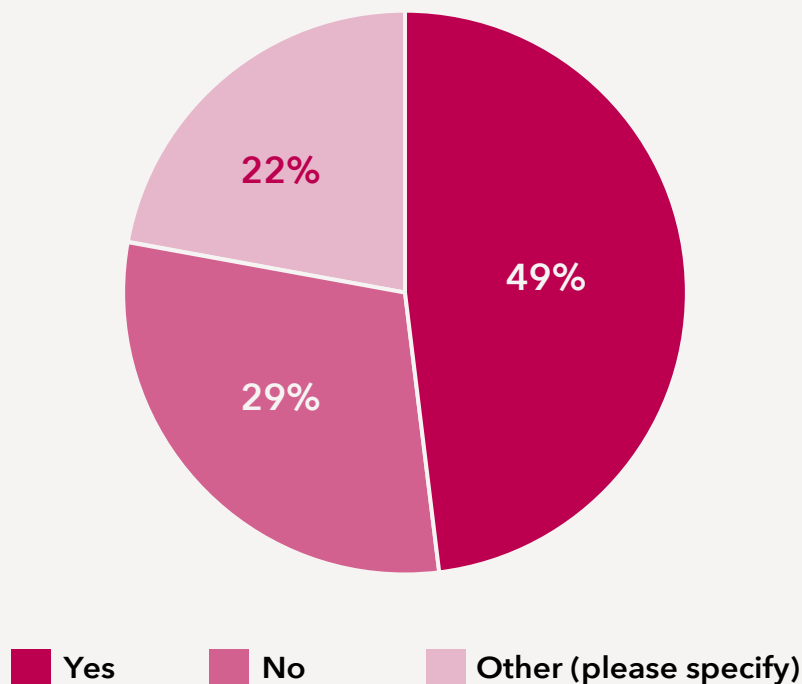
GP[s] have no training and tend to be dismissive. Nothing is joined up and the poor GPs do their best with NO support. Hospital consultants don't want any more work so palm you off to another department or back to GP and the wild goose chase starts again. There are no set medication for the symptoms so you have to go private.

It is important to note that the majority of people surveyed and spoken to for this engagement identified their main 'Long Covid service' to be their GP, as their health board area may not have a dedicated Long Covid service. This was especially the case for people living rurally, who lack access to larger services.

A strong finding from this engagement is, not whether it has been a positive or a negative experience when accessing healthcare services for Long Covid, but, rather, that the vast majority of respondents have been "*unable to engage in the first place*". There are multiple responses highlighting that there are no Long Covid services available, and the respondents feel abandoned and that no one is able, or wants, to help them.

Disengaging from healthcare services

Have you ever disengaged with healthcare services regarding treatment for your Long Covid symptoms?



This research found that :

- 49% of respondents have disengaged from a Long Covid service.
- 29% of respondents have not disengaged from a Long Covid service.
- 22% of respondents chose "other".

Those who chose "other" expanded on this answer, saying that they felt there were no services available for them to disengage from, which further reinforces the previous findings and comments.

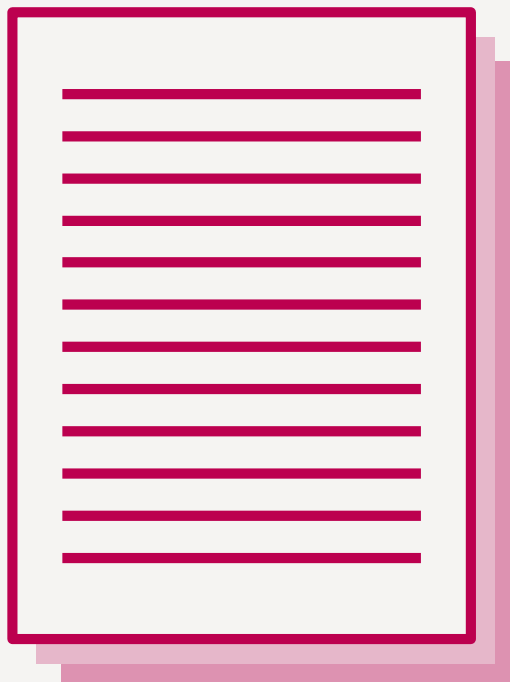


No treatment has been offered and therefore I have not disengaged from something which hasn't been offered.

Participants were asked why they have disengaged from services, however, as highlighted previously, for many this was an irrelevant question as they feel *"it's not us who are disengaging, it's them who have disengaged from us"*. Overall, this sentiment was felt throughout the engagement and felt strongly amongst those living with Long Covid, leading directly to feeling that they are being abandoned by healthcare.



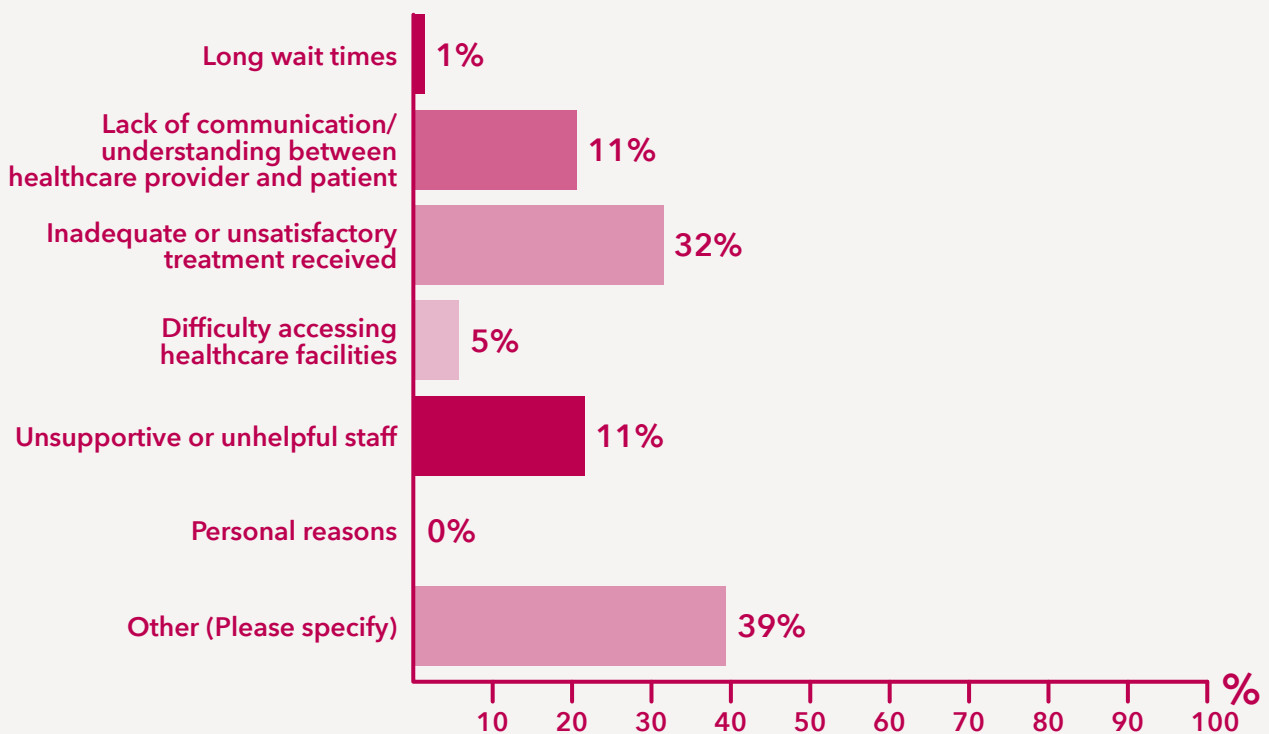
I struggle to understand the statement "disengaging with services" because its more than there are no services and having to fight for whatever referrals we can get and then having to wait many many months for them to come.



However, those who did engage with services, including Long Covid specific services as well as a range of other healthcare services, gave a variety of reasons for disengaging. Trends that were commonly found in the survey responses and discussed in the focus groups can be categorised into the following topics:

- 1% of respondents disengaged due to long wait times.
- 11% of respondents disengaged due to a lack of communication/understanding between healthcare provider and patient.
- 32% of respondents disengaged due to inadequate or unsatisfactory treatment received.
- 5% of respondents disengaged due to difficulty accessing healthcare facilities.
- 11% of respondents disengaged due to unsupportive or unhelpful staff.
- 0% of respondents disengaged due to personal reasons.
- 39% of respondents disengaged due to “other” reasons.

If you have disengaged from healthcare services for your symptoms of Long Covid, why?



32% of respondents said that inadequate or unsatisfactory treatment was received, leading to their disengagement. For example, it was frequently reported by respondents that GPs didn't know where to refer them and performed tests that were felt to be unlikely to lead to support, treatment and diagnosis, and were therefore felt to be unsuitable.



Being told repeatedly that the condition is "too new", that there is not enough known about the condition and therefore nothing can be done. A total lack of any willingness or curiosity to investigate the possible physiological causes of this condition and the causes of long-running symptoms.

In addition, many respondents found that other health professionals they encountered were dismissive of their symptoms and extremely unhelpful. Many respondents spoke of the hurdles they faced when attempting to get treatment and information about their, often life changing, symptoms.



2 year wait times, nothing to help in interim, disbelief by consultants, no acknowledgement of why I am unwell, no alternative testing when NHS emergency tests don't always show the issues.

11% claimed unsupportive or unhelpful staff were key to their disengagement, while 11% cited lack of understanding and/or information as to their key reason for disengaging. Throughout focus group discussion, a lack of trust was an outcome many respondents directly related to their negative relationships and experiences with staff, as well as the feeling that they were more educated in their condition than healthcare professionals are. Due to this lack of trust, respondents do not feel they are receiving adequate care, and this can lead to disengagement from a service.





If I were to go to a doctor and say "I need X" but they're not clued up on the research, or the research doesn't exist, I won't be believed, or they'll treat/refer to humour me. That shouldn't be the case. Patients shouldn't have to become experts in a forlorn attempt to ward off wilful ignorance and the consequent stigma.

It is important to note that when asked why they have disengaged from healthcare services for symptoms of Long Covid, just under half of respondents who chose "other" explained that they would have chosen all or multiple answers from the list and that selecting only one was not representative of their reasoning for disengaging.

What services are people accessing?

67% of respondents advised that they have accessed alternative healthcare or holistic treatments for their Long Covid symptoms, often in place of the NHS services they feel are lacking. These included massage, chiropractor, and reflexology. Many made changes to their diet and added supplements, others found that support groups and counselling helped them. Acupuncture, reiki and herbalists were mentioned, and many said they used hyperbaric oxygen therapy, which was found to be extremely therapeutic, and supportive when self managing Long Covid symptoms.



I have attended neurology, cardiology, gynaecology and ENT via private healthcare because NHS referrals were rejected or wait times were over 6 months. I also attend self funded hyperbaric oxygen treatment and massages.

Many respondents mentioned that they had turned to private healthcare and felt incredibly fortunate to be in the position to do so. Private healthcare was not always feasible long term, if at all, as many respondents were under financial constraints due to their symptoms effecting their ability to work, as well as the cost-of-living crisis.



I have used all my pension savings to try and get well.

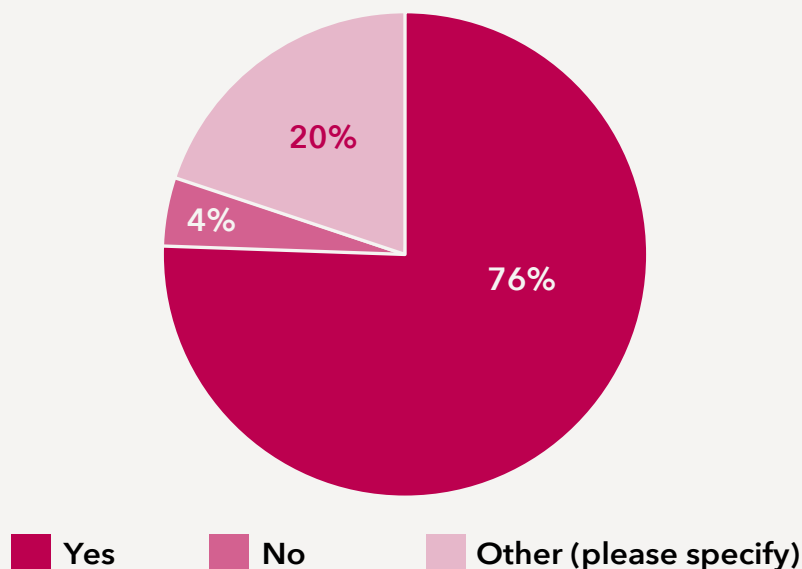


I cannot afford to or I would go private.

In addition to private healthcare services, third sector support services were noted to be extremely helpful, including Long Covid specific organisations, and other organisations who offered Long Covid specific services.

What would we like to see from services?

Are there any specific healthcare services or treatments that you feel are lacking in the current Long Covid healthcare services? If yes, please specify.



- 76% of respondents felt that there are services and treatments lacking in current services specifically catering for Long Covid.
- 4% of respondents did not feel that there are services and treatments lacking in current services.
- 20% of respondents chose "other".

When asked what changes respondents would like to see and what they think is missing for Long Covid services in Scotland there were several suggestions that were offered. At the heart of what respondents want is *"To be believed, understood and supported"* with wider acceptance of the varying symptoms of Long Covid, and for this to be reflected by healthcare professionals. Key to this was further training, information, and communication about Long Covid for frontline healthcare professionals. This training needs to provide all healthcare professionals, including those out with a specific Long Covid service, with a greater understanding of Long Covid, and its varying symptoms, specific testing and more research into the symptoms and possible treatments.



There needs to be a major reconsideration of how Long Covid is dismissed at all levels. Medical staff need to have proper training, and understand the severity of the condition. A lot more could and should be done, and proper resources should be made available for ongoing care.

Respondents believe that there should be dedicated Long Covid specialist services, which include dedicated, trained medical staff as well as Allied Health Professionals. It was felt that having a specialist invested in your care would help to tackle the feeling of receiving adequate care and treatments which are up to date with current research.

When accessing public spaces, especially hospitals or spaces where there is risk of infection, there is concern amongst those living with Long Covid to protect themselves from health risks. On the hand, the attitudes towards not being offered face-to-face appointments was generally negative. It is suggested that more needs to be done to make healthcare environments safe to allow those impacted to attend without risk of re-infection, and most importantly, to offer a choice of a face-to-face or online appointment.

We have previously mentioned in this report that waiting times for referrals and subsequent appointments was felt to be excessive, and this has been highlighted as something that needs to be changed. It is also clear that the same services are not available in all areas of Scotland, and this is something those living with Long Covid felt was unfair – references to the “postcode lottery” were found throughout this research.



A joint up integrated approach eg long Covid clinics or at least pathways that all professionals follow so no disparity between health authorities.

It was suggested that all these changes should be managed under a central Long Covid hub, with all Long Covid specialists available and centrally managed to ensure those living with Long Covid have access to all types of care and treatments.



Most of all, what's needed is a lead practitioner to coordinate investigations and care, not siloed by single body systems. This needs to be someone who is given appropriate status and seen as credible both among professionals and patients. Without both, there won't be the trust or the appropriate treatment.

Additionally, respondents felt that navigating the complex healthcare system was difficult and advocated for support in this area. It was felt that one central Long Covid Clinic would alleviate this difficulty. The need for a holistic, full body, person-centred approach to services was called for by both the survey respondents and the focus group attendees. There needs to be continuity of care and a more joined up approach between specialities and different disciplines. A “one-stop shop” was the most popular suggestion for change.

With regards to Long Covid clinics which are already running, there is acknowledgement that resources are stretched, and especially how this has affected the services offered. Reduced waiting times and more capacity to intake referrals were key priorities for respondents, as well as having an interdisciplinary team available at the clinics.



Try[ing] to live with Long Covid takes its toll on the well being of myself and those who live with me. Its a constant struggle to access appropriate care for someone with a relapsing and remitting illness. There is no service readily available for people with Long Covid - I manage my own care and support. Access to health care is challenging for everyone, for some one with a long term illness, particularly Long Covid it is particularly difficult to get a continuity of care to support managing the condition.

Due to the unpredictable nature of how symptoms of Long Covid affect people, and change on a day-to-day basis, continuity of care was seen to be incredibly important to respondents. When engaging around this issue, respondents said that having a go-to professional to support in the management of changing symptoms would be helpful. Often it was felt that by the time they were seen by a professional, they had already had to self manage their symptoms without any support, and felt that any healthcare intervention was redundant.



Every day and its activities are dictated by long covid. The only really predictable thing about it is that it is unpredictable. I have learned over the past 3 years to manage that unpredictability, but it still severely limits what I can do and when.

80% of respondents said they do not feel adequately informed about the healthcare services available to them to support their Long Covid symptoms. There is a call for information to be circulated more freely, and for information around Long Covid to be standardised. There was a clear trend seen within this engagement that individuals were not aware of what kind of care they were entitled too, what services existed in their local area, and what kind of support or treatment would be available for them.

Conclusion

The community of people with experience of living with Long Covid, or supporting someone living with Long Covid, were passionate about sharing their experiences. They are hopeful that in doing so they can prevent similar negative experiences of their own from happening to others.

This engagement has shown that a large number of people living with Long Covid have experienced symptoms for a number of years, which are often severe, and unpredictable. Most of the people surveyed had attempted to access health and social care services to support their health and wellbeing. They reported their experiences of accessing care was generally negative, but with some positive aspects – for most, this was around relationships with healthcare professionals, especially GPs. GPs were the gateway for many people, with some moving onto other services, and some feeling locked out of being able to access any further service or care. The majority of people who took part in this engagement did not feel that there was a service available to them to disengage from, and were hoping to see a more robust, wrap-around, holistic Long Covid specialised service in the future.

Those who had experienced the Long Covid specific services often felt that the waiting times had a negative impact on their experience, and they did not feel that the care was satisfactory, especially with regards to treatments and support which was available, leading to a lack of trust in healthcare services. Just under 50% of respondents had disengaged from a Long Covid NHS service or had never felt able to engage with a service in the first place. This disengagement has led a number of people to look into private healthcare or alternative treatments to support their symptoms.

People reported there should be more communication and information about services, and what to expect from that service, more widely available. This should be available for the general public and healthcare professionals, and many felt this would help in rebuilding trust. Having a person centred approach to a whole service which understands Long Covid holistically is what respondents have asked for and hope to see from future services.

The ALLIANCE would like to extend its gratitude to everyone who was involved in this engagement - thank you to those who responded to or shared our survey, or who came along to the focus groups.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level. Our vision is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.



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