Service evaluation report

For the Suffolk and Northeast Essex Long COVID Assessment Service

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Service evaluation December 2023-January 2025
Report written by Abigail Webb, February 2025

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Executive summary

The present evaluation of SNELCAS highlights several key findings. Overall, **SNELCAS is effective in improving patients' physical health and quality of life**, with significant gains in self-care, usual activities, and a 10% increase in self-reported health status. Patients praised the service's **emotional support and empathy** from specialists, which helped them feel understood and reassured. **Practical tools** like the Living With app and peer support groups were highly valued, as they reduced isolation and empowered patients with self-management strategies. However, **gaps in communication and follow-ups** left some patients feeling unsupported, especially during long waiting times for referrals and unclear updates. Suggestions for improvement included regular check-ins, better appointment reminders, and more personalised care pathways.

For staff, SNELCAS is generally a positive **working environment**, with effective referral processes and good administrative support. Areas for improvement include enhancing communication with GP practices, addressing hybrid working challenges, and providing additional System One training/integration. Staff also noted inconsistencies in advice and accessibility issues, recommending more face-to-face support and communication.

External services received some mixed feedback, but were overall quite positive. While services like CAB, creative health interventions and Sport for Confidence provided valuable support, others like KiActiv and the Living With app could be improved by simplifying content and offering in-person onboarding. Greater personalisation and consistent evaluations would help ensure these services meet patient needs effectively.

Our recommendations, outlined in the final section of this report, are summarised succinctly below:

1. **Increase outreach to diverse communities** through partnerships with local organisations and targeted community engagement.
2. **Provide cultural competence training** for staff to improve trust and communication with underrepresented groups.
3. **Regularly monitor referral data** and adjust outreach efforts to ensure equitable access.
4. **Tailor 6-week self-management sessions** by symptom severity and individual needs.
5. **Offer smaller group sizes** for personalised advice and increased interaction.
6. **Record and archive sessions** for patients to access at their own pace.
7. **Simplify session content** and reduce cognitive demands with shorter, digestible formats.
8. **Introduce regular clinician-led check-ins** every 4–6 weeks for consistent communication.
9. **Develop a centralised patient portal** for tracking appointments, referrals, and available services.
10. **Automate appointment reminders** and provide multi-channel follow-ups.

11. **Assign care coordinators** to improve continuity of care and follow up on outstanding referrals.
12. **Expand peer support opportunities** with bi-weekly sessions and moderated online platforms.
13. **Standardise virtual meeting protocols** and hold regular in-person team check-ins to improve staff collaboration.
14. **Provide additional System One accessibility** and centralise referral forms for administrative efficiency.
15. **Conduct independent evaluations** of external services to align patient experiences with supplier reports.
16. **Simplify external service processes** and offer in-person onboarding to improve usability.

Preamble

Project members

Project members from University of Suffolk and East Suffolk and North Essex NHS Foundation Trust (ESNEFT) and their respective roles are outlined below.

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Funders

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Ethical approval and data sharing

The project was registered with the Clinical Outcomes team at ESNEFT in February 2024, as an audit and service evaluation. The project has also received ethical approval from the University of Suffolk Research Ethics Committee in December 2023 RETH(S)23_038.

A Data Sharing Agreement between ESNEFT (data controller) and University of Suffolk (data processor) was obtained in October 2024, for the purpose of sharing the following data:

- Patient ID (omitting name information)
- Age at referral
- Source of referral
- Referral date

- Initial assessment date
- Discharge date
- Sex
- Ethnicity
- Postcode (first element)
- EQ-5D-5L scores at each time point between first, interim and discharge appointments

1. Introduction

1.1. The Suffolk and Northeast Essex Long COVID Assessment Service

The Suffolk and Northeast Essex Long COVID Assessment Service (SNELCAS) is a specialised service designed to support individuals experiencing prolonged symptoms following a COVID-19 infection. Long COVID, also known as Post COVID-19 Syndrome, encompasses a range of symptoms that persist for more than 12 weeks after the initial infection and are not explained by alternative diagnoses. The service was established rapidly in 2021 to meet emerging demands during the pandemic, to meet core criteria set out in the guidance for NHS England 2021/22 Long COVID plan (NHS, 2021), in order to: (i) offer multidisciplinary assessments to provide consistent services, (ii) ensure provision for those affected, including those never admitted to hospital or tested for COVID-19, (iii) ensure equal access and utilisation of healthcare services across the local population. Patients' symptoms can vary widely and may include fatigue, breathlessness, low mood, anxiety, aches and pains, loss of appetite, and cognitive difficulties such as brain fog. Patients referred to SNELCAS pathway are typically referred by their General Practitioners (GPs), often because they have experienced symptoms of long COVID for 12+ weeks. The referral process typically involves the completion of screening questions, an oxygen saturation reading, chest X-ray, and blood tests. Other assessments regarding self-report views of facets of physical and mental health are primarily conducted over the phone, with options for face-to-face appointments when necessary. Clinics are available in West Suffolk, Ipswich, and Colchester, and the service is primarily serving adults.

SNELCAS is a dynamic service and collaborates with various healthcare professionals, including respiratory physiotherapists, occupational therapist, speech and language therapists, nurses, medical staff, and mental health specialists to provide a multidisciplinary approach to care. This integrated model ensures that patients receive comprehensive support tailored to their specific needs, but support from external appendages offers bespoke support to those experiencing some of the real-world impacts of long COVID. For example, social support advice through Citizens Advice, creative health and sports and physical pacing services.

1.2. Present service evaluation: Scope and objectives

The present evaluation adopted a mixed-methods approach across multiple workstreams (WS), to assess (in no particular order): (1) demographics of the patient population and in relation to local areas, (2) referral routes, (3) waiting periods between referral, initial assessment and discharge, (4) indicators of physical health and quality of life before compared to after engagement with SNELCAS, (5) perceived impact on patient health and wellbeing according to service users, (6) perceived impact on patient health and wellbeing according to service staff, (7) staff workplace satisfaction, and (8) an overview of the external service suppliers commissioned by SNECLAS to complement and support patients' recovery from long COVID.

Workstreams and their associated objectives are summarised in Table 1 below.

Section	Objective(s)	Data source	Status
SNELCAS patient demographics	Assess whether SNELCAS patients represent the demographic of the two key areas it serves	SNELCAS source data; Office for National Statistics; 2021 Census	Complete
Referral timelines	Outline waiting times between referral-initial assessment, initial assessment-discharge, and source of referrals	SNELCAS source data	Complete
EQ-5D-5L: Before and after SNELCAS	Assess the difference between EQ-5D-5L scores at initial appointment vs. discharge	SNELCAS source data	Complete
SNELCAS service user feedback	Assess perceived efficacy of service according to patients	New primary data	Complete
SNELCAS service staff feedback	Assess perceived efficacy of service according to service staff	New primary data	Complete
SNELCAS Peer Support Group feedback	Assess perceived efficacy of peer support group according to patients	New primary data	Complete
External service suppliers: Offerings and impact	Map the key external service suppliers and their impact according	New primary data	Complete

	to SNELCAS patients	

Table 1. Outline of objectives and data source for each workstream.

2. Patient demographics: Are SNELCAS patients representative of the demographic for the area that it serves?

According to SNELCAS source data, between 04/12/2020 and 12/07/2024 the service received 1, 787 patient referrals. The demography of referrals is outlined in Table 2, below.

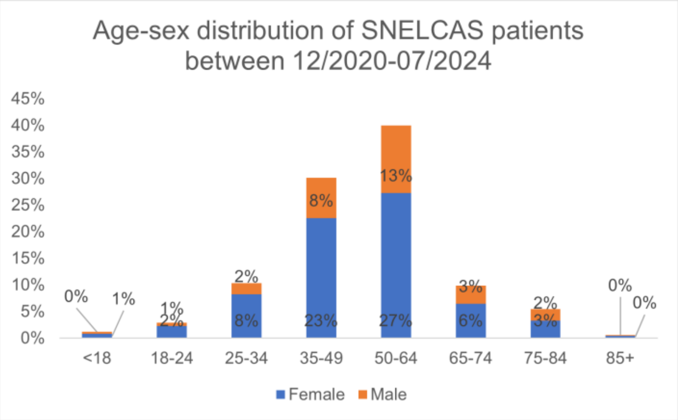

Figure 1. Distribution of age groups and gender for SNELCAS patients referred to the service between 2020 and 2024.

Sex	Age (years)	Ethnicity	Patient location
Female: 71% Male: 29%	<18: <1% 19-24: 3% 25-34: 10% 35-49: 30% 50-64: 40% 65-74: 10% 75-84: 5% 85+: 1%	White: 84% Asian or Asian British: 2% Unknown/not stated: <1% Mixed ethnic groups: 1% Black, Black British, Caribbean or African: 1% Other ethnic group: 6% Omitted: 6%	Suffolk: 55% Essex:40% Norfolk: <1% Cambridge: 4% Chelmsford: <1% Other:1%

Table 2. Breakdown of demographics for SNELCAS patients between 2020 and 2024

The majority of SNELCAS patients are from Suffolk or Essex, between the age of 50 and 64 years, and are more likely to be White and Female. This is somewhat representative of the true population of Suffolk, where the greatest proportion of individuals are aged between 50-64 years (and decline linearly either side of this age bracket), and gender is evenly split. In Essex, the greatest proportion of individuals are aged between 35-49 years, followed closely by 50-64 years, and again regarding gender is evenly split. SNELCAS is somewhat representative of both populations in terms of age, though disproportionately serves more women than men in the Suffolk and Essex areas. Regarding ethnicity, the populations of both Suffolk and Essex are predominantly White (~87%, ~89%, respectively), followed by Asian (2.3%, 4.2%, respectively), Mixed (or multiple ethnic groups) (2.3%, 1.5%, respectively), Black (1.3%, 3.4% respectively) ethnicities. The population of SNELCAS patients is representative of this group insofar as that most patients are White, and a small minority are Asian, Black or Mixed/Other ethnic groups. Although a sample of ~1,600 is relatively small in comparison to the populations of the two counties, we would expect SNELCAS to serve a greater number of individuals who are from Asian, Mixed (or multiple ethnic groups), or Black ethnic backgrounds.

In evaluating the SNELCAS service, it is evident that the patient demographic aligns well with the local population in terms of age distribution, and includes fair representation of age brackets commonly affected by long COVID [1]. Although there is a disproportionate number of women accessing the service, this divergence from the local population's even gender split is anticipated, given that long COVID tends to affect women more than men [2 ,3]. However, the representation of patients in terms of ethnicity does not align with the local populations. We would expect to see more individuals from Asian, Mixed (or multiple), or Black ethnic backgrounds, which is particularly important given that long COVID disproportionately affects individuals from Black, Asian and Minority Ethnic (BAME) backgrounds and with variable symptomology [3, 4, 5].

Sources: 2021 Census and Office for National Statistics

3. Referral timelines

3.1. Sources of referral

Sources of referral formed 4 categories. The most common referral source code was GP (National code: 3), which constituted 69% of referrals, followed by General Practitioners (30%), 111 Service (1%) and Long COVID Assessment Service (<1%). Note that for GP National code 3, this typically refers to a referral that is considered a "routine" or "standard" referral, meaning it is not urgent but should be seen by a specialist within a reasonable timeframe.

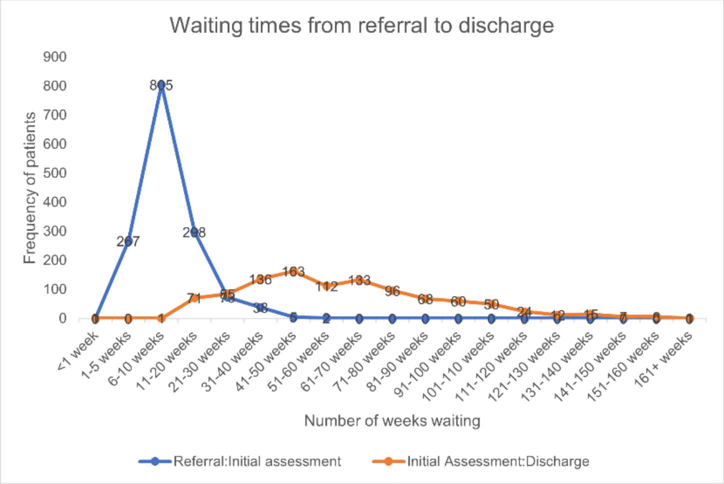

Figure 2. Distribution of wait time between point of referral to initial assessment (blue) and initial assessment to discharge (orange).

3.2. Referral-initial assessment-discharge timelines

Of approximately 1, 741 patient referrals received between 04/12/2020 and 12/07/2024, 1, 135 (65%) were discharged from the SNELCAS service.

Across all patients, the average waiting time between *referral* and *initial assessment* was 68 days. The shortest wait time was 3 days, and the maximum was 412 days. The majority of SNELCAS patients completed their initial assessment at 6-10 weeks, as shown in Figure 2.

For discharged patients, the average time between *initial assessment* and date of *discharge* was 423 days. The shortest period of time between initial assessment and discharge taking place was 0 days, suggesting that on a very small number of occasions a patient may have no longer required support from SNELCAS by the time they received their initial assessment. The maximum was 1, 133 days. The majority of discharged SNELCAS patients were discharged between 31 and 70 weeks, as shown in Figure 2.

Therefore, most patients had their initial assessment within **6-10 weeks**, and once assessed the **average time** until discharge was **61 weeks** (about 14 months). Some patients were discharged immediately (**0 days**), while others received care from SNELCAS for up to **162 weeks** (over 3 years). These data highlight the variability in wait times and the duration of care, with most patients experiencing moderate waiting periods but some facing significantly longer waits. Implications of longer waiting periods and time lapses between appointments are highlighted by service users as an area for improvement, outlined in Section 5.

Waiting times are visibly very widely spread, which reflects the short preparation time for the SNELCAS service to become ‘live’, and also periods of higher referral rates following acute COVID-19 spikes. Waiting times, overall across time, have reduced and stabilised.

4. EQ-5D-5L: Before and After SNELCAS

For every patient, EQ-5D-5L scores were captured at multiple time points, up to a maximum of 7 times. Note that not every patient received a total of 7 EQ-5D-5L scores, due to differences in the time between initial referral and discharge across patients. While 100% of patients were scored at timepoints 1 and 2, only 1% were scored at timepoint 7, demonstrated in Figure 3. The average period of time between timepoints 1 and 2, where all patients received EQ-5D-5L score recording, was 149 days. Between average time between timepoints 2 and 3 (58% of patients) was 154 days, 3 and 4 145 days, 4 and 5 156 days, 5 and 6 147 days, and 6 and 7 104 days, shown in Figure 3.

To compare differences in EQ-5D-5L scores *before* versus *after* engagement with SNELCAS, we extracted all EQ-5D-5L scores taken at the *first* and *last* timepoint of all discharged patients (n=1,157). At a glance, Figure 4 (a) shows that average scores for Self-care and Usual Activities are decreased at discharge compared to first measures. In other words, the average patient discharged from SNELCAS will report a one-step improvement in their self-care and ability to participate in usual activities, with an improvement from “slight problems” to “no problems” for self-care and “moderate problems” to “slight problems” for their ability to perform usual activities. Average scores for Mobility, Pain/Discomfort and Mood do not appear to differ. Although this suggests improvements in only two of the 5 dimensions, in the following sub-sections we have used Wilcoxon Signed Rank tests to explore statistically significant differences between the *distribution* of scores, as this is more likely to reveal any meaningful shift than average scores.

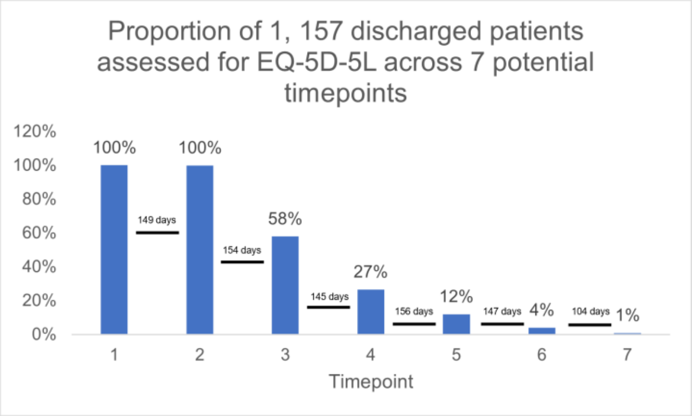

Figure 3. EQ-5D-5L scores were generated for each patient at up to 7 time points.

Indeed, Figure 4 (b) and (c) below illustrate the distribution of EQ-5D-5L scores for before and after SNELCAS engagement, showing that levels of reported severity for each of the 5 dimensions are generally reduced by the time patients are discharged from SNELCAS. The following subsections address changes in these distributions for each of the 5 dimensions.

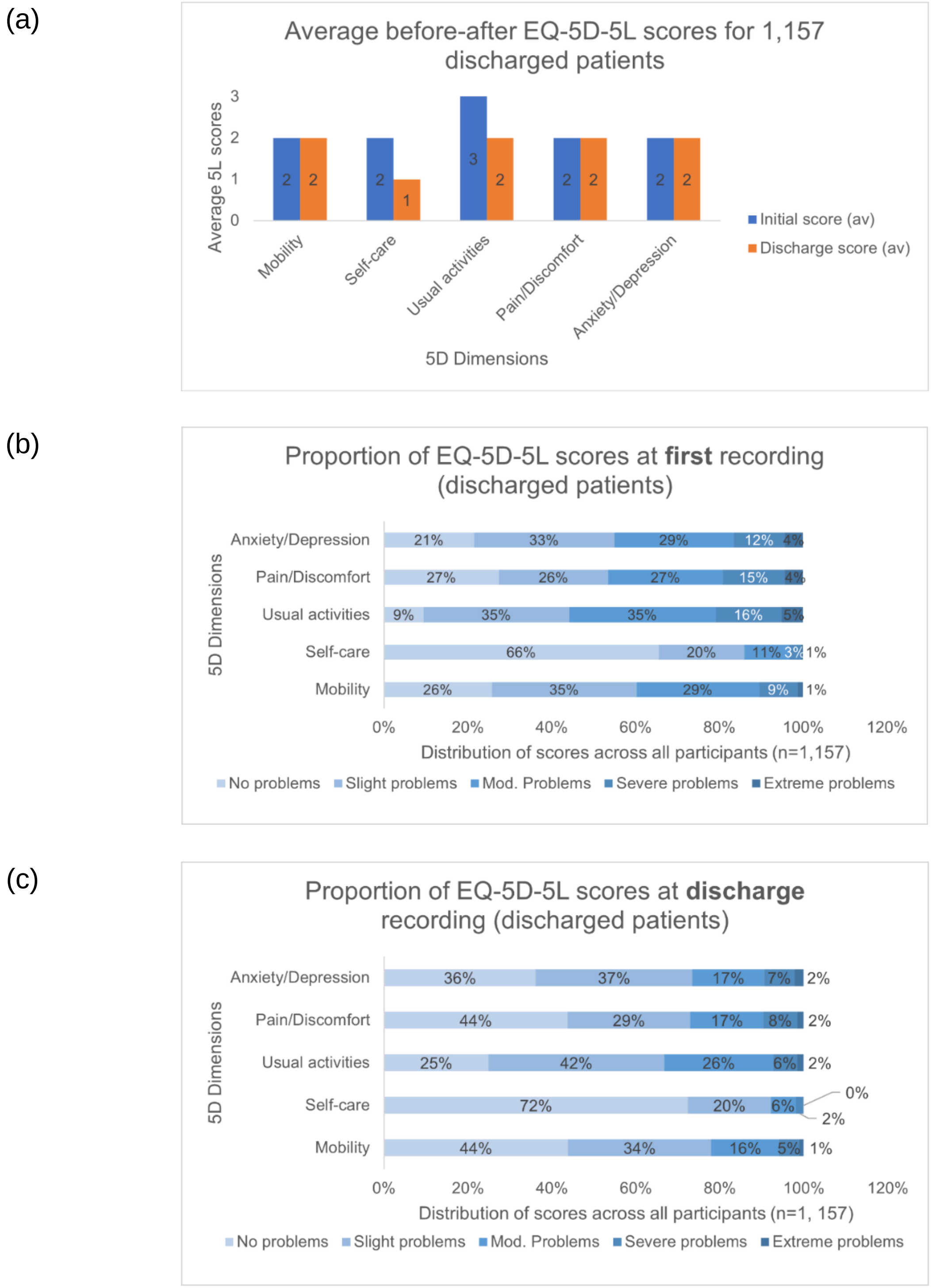

Figure 4. (a) Average scores for each of the EQ-5D-5L dimensions, at first measure (blue) and discharge (orange). Averages do not change for all dimensions, however Figures (b) and (c) show the *distribution* of scores at first and discharge recording (respectively), and respective tests show statistically significant shifts in the distribution of scores towards a positive polarity that indicates improved health.

4.1. Mobility: Before and after discharge

For 1,157 discharged patients, average scores for Mobility suggest no difference in patients' rating of their Mobility performance before versus after their engagement with SNELCAS. However, we found a statistically significant difference between the distribution of 'Before' and 'After' conditions, despite their identical averages. This means that while the typical (middle) score for Mobility did not change, there were meaningful shifts in how the scores were distributed. Specifically, 'After' scores for Mobility are lower than 'Before' scores overall, such that an average SNELCAS patient is more likely to rate their Mobility as less severe after they have been discharged from the service compared to when they were initially referred. These findings are summarised in Table 3 and illustrated Figure 5 (a).

Mean		**Median**	
Initial	Discharge	Initial	Discharge
2	2	2	2

Wilcoxon Signed-Rank test

$Z = -12.5$, $p < .001$, r = -0.5.

Table 3. Mobility: Wilcoxon signed-rank test showing a statistically significant shift in the distribution of mobility scores in the direction corresponding to improvement.

4.2. Self-care: Before and after discharge

For 1,157 discharged patients, average scores for Self-care decreased by 1 score e.g., from "Slight problems" to "No problems" for the average SNELCAS patient. Median scores did not differ. Again, we found a statistically significant difference between the 'Before' and 'After' conditions, showing meaningful shifts in how the scores were distributed. Specifically, 'After' scores for Self-care are lower than 'Before' scores overall, such that an average SNELCAS patient is more likely to rate their ability to maintain Self-care as less severe after they have been discharged from the service compared to when they were initially referred. These findings are summarised in Table 4 and illustrated Figure 5 (b).

Mean		**Median**	
Initial	Discharge	Initial	Discharge
2	1	1	1

Wilcoxon Signed-Rank test

$Z = -6.1$, $p < .001$, r = -0.3

Table 4. Self-care: Wilcoxon signed-rank test showing a statistically significant shift in the distribution of self-care scores in the direction corresponding to improvement

4.3. Usual activities: Before and after discharge

Mean		**Median**	
Initial	Discharge	Initial	Discharge
3	2	3	2

For 1,157 discharged patients, average scores for Usual activities decreased by 1 score e.g., from “Moderate problems” to “Slight problems” for the average SNELCAS patient. Median scores reflected the same difference. Again, we found a statistically significant difference between the 'Before' and 'After' conditions, showing meaningful shifts in how the scores were distributed. Specifically, ‘After’ scores for Usual activities are lower than ‘Before’ scores overall, such that an average SNELCAS patient is more likely to rate their (in)ability to undertake usual activities as less severe after they have been discharged from the service compared to when they were initially referred. These findings are summarised in Table 5 and illustrated Figure 5 (c).

Wilcoxon Signed-Rank test

$Z = -15.9$, $p < .001$, r = -0.6

Table 5. Usual activities: Wilcoxon signed-rank test showing a statistically significant shift in the distribution of usual activities scores in the direction corresponding to improvement

4.4. Pain/Discomfort: Before and after discharge

For 1,157 discharged patients, average scores for Pain and Discomfort suggest no difference in patients’ rating of their Pain/Discomfort performance before versus after their engagement with SNELCAS. However, a statistically significant shift in the distribution of scores shows that ‘After’ scores for Pain/Discomfort are lower than ‘Before’ scores overall, such that an average SNELCAS patient will typically rate their pain and discomfort as less severe after they have been discharged from the service compared to when they were initially referred. These findings are summarised in Table 6 and illustrated Figure 5 (d).

Mean		**Median**	
Initial	Discharge	Initial	Discharge
2	2	2	2

Wilcoxon Signed-Rank test

$Z = -12.9$, $p < .001$, r = -0.5

Table 6. Pain/discomfort: Wilcoxon signed-rank test showing a statistically significant shift in the distribution of pain/discomfort scores in the direction corresponding to improvement

4.5. Anxiety and Depression: Before and after discharge

For 1,157 discharged patients, average scores for Anxiety and Depression suggest no different in patients’ rating of their Anxiety and Depression before versus after their engagement with SNELCAS, a statistically significant shift in the distribution of scores shows that ‘After’ scores for Anxiety and Depression are lower than ‘Before’ scores overall, such that an average SNELCAS patient will typically rate Anxiety and Depression as less severe after they have been discharged from the service compared to when they were initially referred. These findings are summarised in Table 7 and illustrated Figure 5 (e).

Mean		Median	
Initial	Discharge	Initial	Discharge
2	2	2	2

Wilcoxon Signed-Rank test

Z = -11.3, *p* < .001, r = -0.4.

Table 7. Anxiety/depression: Wilcoxon signed-rank test showing a statistically significant shift in the distribution of anxiety/depression scores in the direction corresponding to improvement

4.6. Visual Analogue Scores for self-reported health: Before and after discharge

Across 1,157 discharged patients, a statistically significant increase in VAS scores after compared to before measurements, showing that on average, SNELCAS patients' self-report ratings of their own health status increased by around 10% on the Visual Analogue Scale. In other words, patients' rating of their own health status shifted towards the positive end of the scale denoting positive overall health. Findings are summarised in Table 8.

4.7. Summary

Mean (SD)	
Initial	Discharge
56.4 (19.8)	65.8 (20.1)

Paired samples t-test

T(1,157) = 11.37, *p* < .001

Table 8. VAS scores: Paired samples t-test showing a statistically significant increase in VAS scores in the direction corresponding to improvement

Analysis of EQ-5D-5L scores from 1,157 discharged SNELCAS patients shows significant improvements in all dimensions. For **Mobility**, while average scores remained unchanged, the distribution showed a trend towards less severe ratings post-discharge. **Self-care** saw a clear improvement, with average scores dropping from "Slight problems" to "No problems," indicating enhanced self-care abilities. **Usual Activities** also improved, with patients reporting fewer difficulties, shifting from "Moderate" to "Slight problems." Although average scores for **Pain/Discomfort** and **Anxiety/Depression** showed no visible change, a significant shift in score distributions suggested patients experienced these issues less severely after discharge. Finally, the **Visual Analogue Scale** (VAS) for self-reported health reflected a marked improvement, with a 10% increase in self-reported health status, indicating overall better health perception post-engagement with SNELCAS.

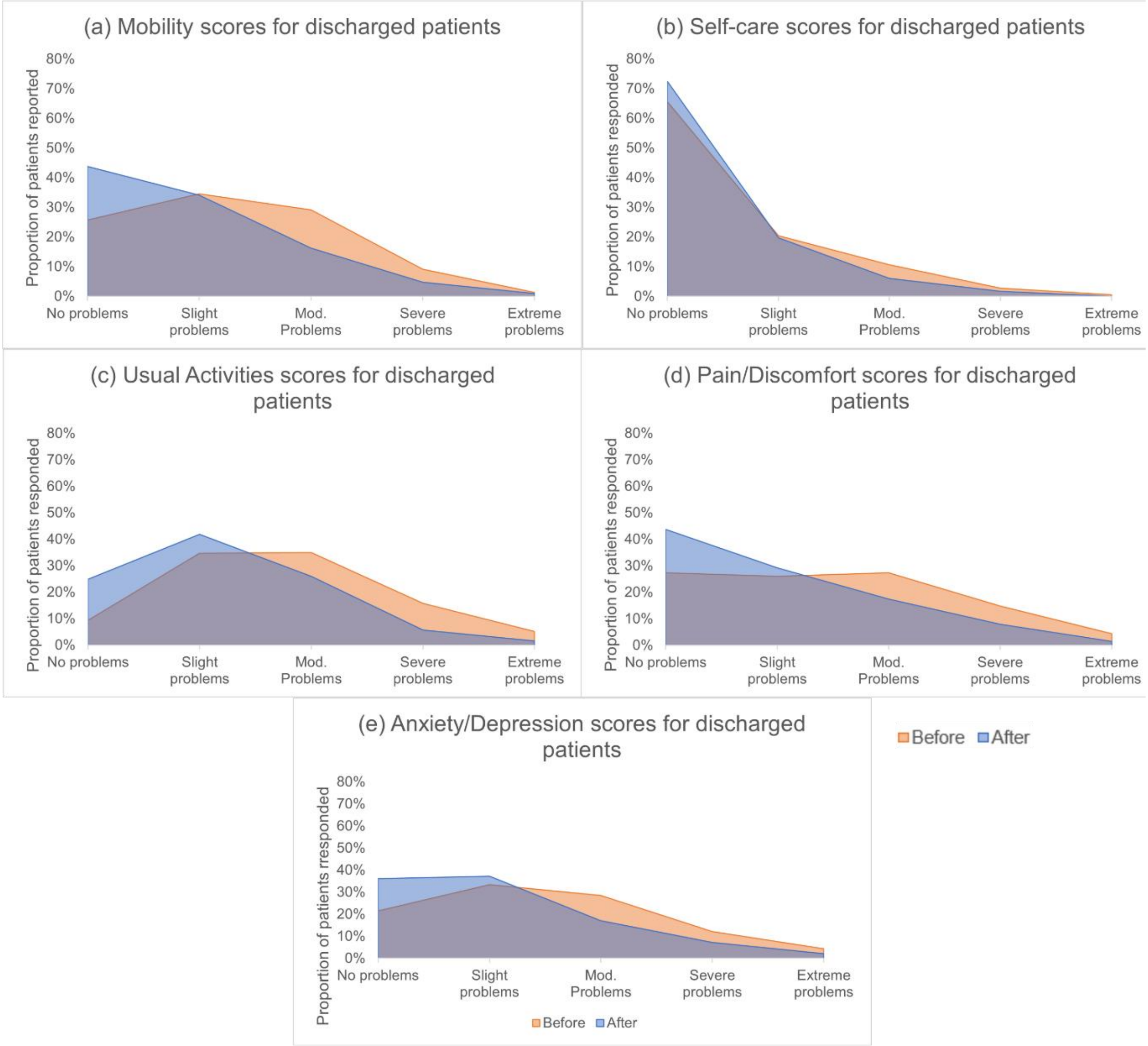

Figure 5. Distribution of scores for each of the EQ-5D-5L dimensions, where shifts are visible between ‘before’ (initial assessment) and ‘after’ (discharge) timepoints.

5. Service user feedback

5.1. Methods

Patients were invited to participate in an anonymous online survey hosted by the University of Suffolk but disseminated via SNELCAS administrators.

The survey included items corresponding to the themes outlined below, and the majority were alterative forced choice responses and/or statement items with associated Likert responses. Section 5.9. includes qualitative findings from free-text-response items presented to patients at the end of the survey.

5.2. Patient demographics

Two-hundred-and-twelve SNELCAS patients completed an anonymous, online survey. Seventy percent were female, 29% were male, one individual omitted a response, and 3 individuals reported that their gender was incongruent with the sex they were assigned at birth. Patient age varied between 19- and 87-years, and the average age was 57-years, see Figure 6. Ninety-two percent identified as heterosexual, 2% as gay or lesbian, 2% as bisexual, and 4% omitted details of their sexual orientation. For 99% of patients surveyed, English was their first language, and 90% were White English, Welsh, Scottish, Northern Irish or British, 5% White other, 1% White and Asian, and 1% Asian British, Black British African, or Black British other. In comparison to the typical demography of SNELCAS patients (see ‘Patient demographics’, above), our sample is consistent insofar as that our population of surveyed service users were more often female, around 57-years of age, and more likely to be White, followed by Asian, Black, or British Other ethnicities.

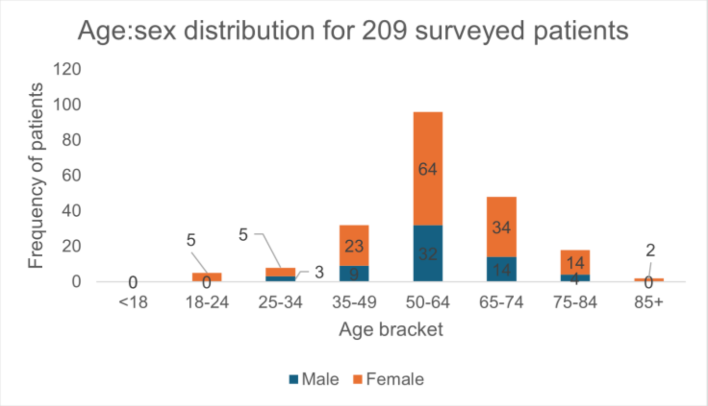

Figure 6. Gender and age distribution of the 209 surveyed patients.

Visits to SNELCAS locations were equally spread across Ipswich, Colchester and West Suffolk sites, with some patients reporting having visited more than one site. Notably, however, 21% said that they had not attended a visit at any of these sites.

This is perhaps not surprising given that many consultations are conducted over the phone, and patients may receive onward referrals to sub-specialities external to SNELCAS. It may also be that when responding to this question, patients were specifically considering the location of SNELCAS appointments rather than any of those organised as part of subspecialty or onward referrals arranged by SNELCAS.
Patient experience of the referral process

Patients were asked how they **first found out about SNELCAS**. The majority (89%) of patients said that prior to their referral, they had *not* heard about SNELCAS. Eight percent of patients said that they had already heard of or knew about SNELCAS before their referral, often through a friend or because they themselves work in healthcare, or they had read about it in ESNEFT literature (e.g., website). Two percent said that they had previously noticed SNELCAS signage in the community e.g., bus advertisements.

When asked about **how they were referred to SNELCAS**, 44% of patients were referred to SNELCAS by their GP who suspected they may have long COVID, and 46% of patients who approached their GP *themselves* with the belief that they may be suffering from long COVID. For the latter ~half of all patients, 35% said that their GP agreed and proceeded with a referral to SNELCAS, but the remaining 10% said that their suggestion of having long COVID was initially met with disagreement from their GP. The leading explanation was that patients had visited their GP on several occasions with consistent symptoms and/or having been tested for a variety of symptoms (8%), followed by cases where their symptoms were initially misdiagnosed as relating to anxiety, depression, or weight related factors (4%). Two participants also reported that they required a family member to attend their appointment with them to support their case.

> “*I was very poorly for pretty much all of 2022. Nearly lost my job several times. My GP were reluctant to pin post COVID as a label to me as bloods repeatedly showed me to be a picture of health. Despite having tonsillitis/chest infection/debilitating temperatures/throat infections / stomach bugs once a fortnight, support wasn't readily available*”

> “*I was told my symptoms were down to being anxious due to being at the GP surgery. I had to go to the doctor a couple of times and felt like they did not take my symptoms seriously to refer me. It sometimes felt like I was being OTT or difficult*”

> “*When I had COVID, everything hurt joints, bones. afterwards I was still left with pain in joints, it has taken 3.5yrs for my GP to agree and she referred me to COVID clinic. Where I was diagnosed with long COVID.”*

For the remaining 8% of all surveyed participants, referrals to SNELCAS were made following either a referral made directly by a healthcare professional external to their GP practice e.g., a CFS specialist, accident and emergency staff, or following recommendation that the patient book an appointment with their GP specifically to request the referral e.g., following a regular visit to a diabetes nurse.

Seventy-six percent of participants agreed that the **reason for their referral** to SNELCAS was explained clearly to them in a way that they could understand (49% “[agree] completely”, 27% “[agree] to some extent”), whereas 13% said that the reason for referral was *not* explained clearly to them. Eleven percent omitted a response.

Eighty-nine percent of patients agreed that the **referral letter or email** they received from SNELCAS was “clear and helpful” in terms of the information it provided about who to contact, recovery resources and next steps (63% “[agree] completely”, 26% “[agree] somewhat). Only 1% said that this information was insufficient, on the basis that (1) the amount of information received was described as overwhelming, and (2) difficult to digest for somebody with dyslexia. Ten percent omitted a response.

5.3. Patient experience of the initial assessment

The majority of initial assessments took place via telephone (61%), followed by face-to-face appointments (35%), then videocall (4%).

Regarding *preferences* for the **mode by which the initial assessment was conducted** were made, face-to-face assessments were the preferred method by patients, followed by video call and then telephone. Almost all (99%) patients who received their initial assessment via a face-to-face appointment said that they were happy with this method, where only one patient said that they would have preferred an alternative. For the 4% of patients who received their assessment via video call, most were satisfied that this was their preferred method whereas. For the 61% of patients who received their initial assessment via telephone call, most (72%) said that this was their preferred method, while others (9%) said that they wish they had chosen an alternative method, or importantly, that they would have liked an alternative method but were not given a choice (19%). Although most initial assessments take place via telephone calls, patients are more satisfied with the mode of assessment if it occurs face-to-face or video call.

Patients were asked whether **SNELCAS staff possessed the necessary information they needed about them and their referral at the initial assessment**. Eighty-four percent of patients agreed that staff appeared to have all the information they needed (47% “[agree] completely”, 37% “[agree] somewhat”). Seven percent reported that key information was missing at their initial assessment, such that they felt they had to relay information previously explained to their GP/HCP. Five of these patients, however, did acknowledge that the likely cause of this was the incompatibility of data systems. Three patients felt that their appointments were rushed, or impersonal, without enough time to fully describe the impact of their symptoms on their daily life. Responses are shown in Figure 7.

> “*Was referred for symptoms that the professional didn't seem aware of. Had to inform them during the 'other' symptoms section at the rushed end of the appointment.”*
>
> *“Most of my records [were missing], re meds, history as the system didn't talk to my GP Surgery network”*

> *“She didn’t refer to my specific problems but just went through a list on her computer and didn’t even look at me”*

Nine percent omitted a response.

Patients were also asked whether, at the end of their initial assessment, they received all the necessary **information about what the next steps would be**, including how long they would be waiting. Eighty-six percent of patients agreed that they left the initial assessment knowing what the next steps would be (73% “[agree] completely”, 13% “[agree] somewhat”). Leading comments from the remaining 14% of patients were that (1) patients left their appointment not knowing what the next steps would be, (2) they were informed of the next steps but of their timescale, and (3) long lapses between communication e.g., still waiting to be contacted or the contact itself took years. Responses are shown in Figure 7.

> *“I still have no idea how long I'm going to be waiting to get onto the classes that were recommended. I still don't know what they all were - my memory isn't as good as it used to be, and I was sent no follow up information after the assessment.”*
>
> *“Information that was missing was a proper treatment plan for me, not being told exactly when I would be seen by an occupational therapist and what they could even do for me besides giving me mobility aids that I don't need. I was not given any information about what they could do to help me, just that I needed to see an occupational therapist next but was not told why and there was no clear explanation for that decision.”*

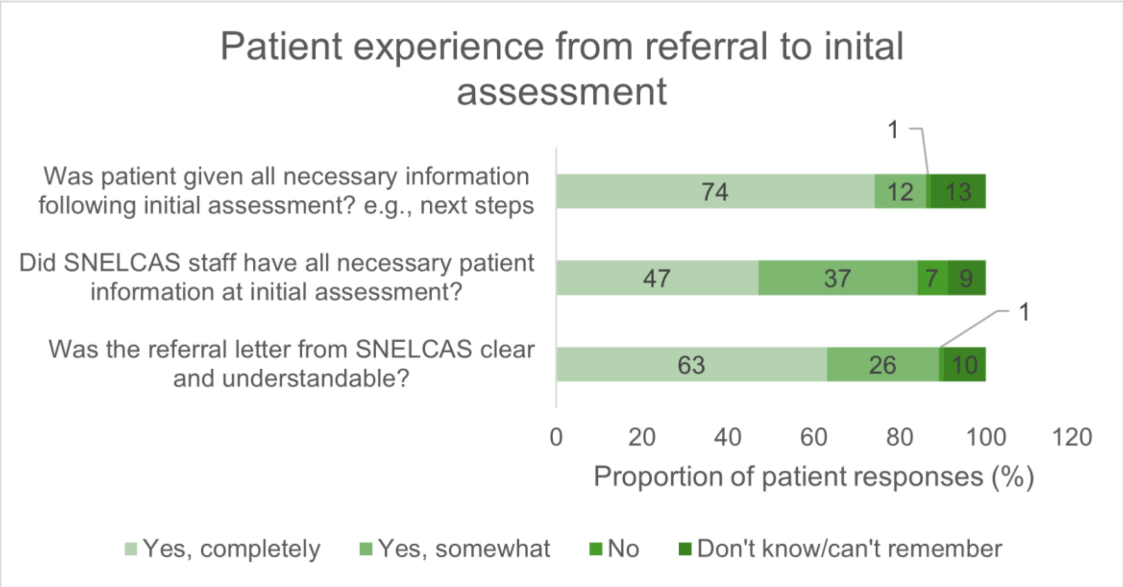

Figure 7. Survey responses to each of the three statements corresponding to 3 themes titled in the left column.

5.4. Patients’ involvement in their care and treatment

The majority (78%) of patients felt sufficiently involved in decisions made about their care and treatment, while they were engaged with SNELCAS. Eleven percent responded neutrally to this question. For the remaining 11% of patients who did *not* feel sufficiently involved in the decision-making process. Responses are shown in Figure 8.

5.5. Treating patients with respect and dignity

The majority (92%) of patients felt that they were treated with respect and dignity while they were engaged with SNELCAS. Four percent responded neutrally, and only 2% responded that they did *not* feel treated with respect and dignity. Responses are shown in Figure 8.

5.6. Helpfulness and clarity of information received from SNELCAS

The majority (83%) of patients found information they received from SNELCAS to be both helpful and clear. Twelve responded neutrally, and 5% did *not* find information to be clear and/or helpful enough. Responses are shown in Figure 8.

5.7. The perceived impact of SNELCAS on patients’ recovery journey

The majority (73%) of patients felt that their engagement with SNELCAS had positively impacted their journey to recovering from long COVID. Sixteen percent responded neutrally, and 9% did *not* feel that the service had positively contributed to their recovery journey. When asked about their experience of SNELCAS overall, 81% of patients agreed that their experience of the service was positive. Thirteen percent were neutral, and 5% responded that they did not have a positive experience. Responses are shown in Figure 8.

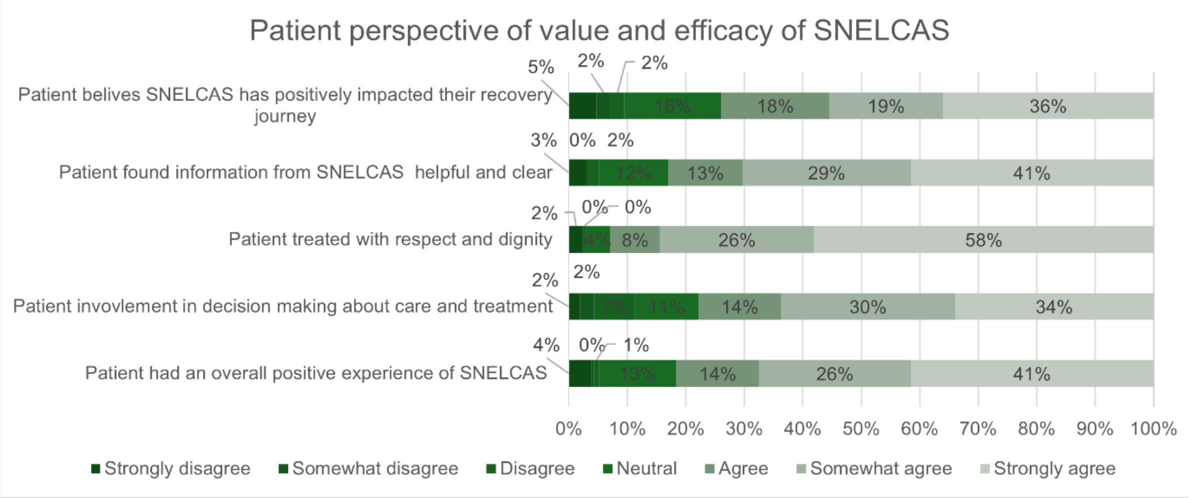

Figure 8. Breakdown of patients' survey responses for items corresponding to each of the 5 themes titled in the left column.

5.8. Qualitative feedback: What about SNELCAS do patients find particularly valuable and/or useful?

We asked all patients "What about your overall experience of SNELCAS was particularly useful and/or valuable to you?". One-hundred-and-seventy-three patients provided a response (81% of all surveyed patients), and from these 5 themes were identified.

Theme 1. Support and empathy: The importance of talking to a specialist who knows long COVID

Emotional support is crucial for a positive experience of SNELCAS. Many respondents emphasised the importance of *"having someone to talk to who understands [the] condition"*, feeling *"understood"*, *"supported"*, *"being listened to*" and reassured by staff. **Validation of the patient's experience** is also invaluable, that long COVID is a serious condition, to recognise that the patient experience is real:

> *"Always felt listened to and understood...even when I felt like a fraud in myself."*
>
> *"It was such a help to be able to talk to someone who understands what I am going through"*
>
> *"The reassurance that [symptoms] was real! That over time I should improve"*
>
> *"To be acknowledged as having an illness and the encouragement and the hope given by the clinicians."*
>
> *"Having someone to talk to who understands the impact of my condition."*
>
> *"Not being judged was such a nice change. Being told that I would improve, explaining what was going on with my breathing issues, and that I had to be gentle with myself as so much was going on for me to cope with physically and mentally. I could tell that she really cared. I was told I would be a long hauler but things would change for me to some extent"*
>
> *"The initial consultation was such a breakthrough for me, to be listened to by someone who had a thorough understanding of all my 'random' symptoms, who had compassion for how difficult it has been, and who confidently advised next steps and available support - I was so happy and relieved. […] The most valuable I suppose is that I feel supported by people who understand what I've been experiencing, and they have the knowledge and tools to help"*

Theme 2. Accessibility to services, onward referrals, and courses

Patients particularly appreciated the **co-ordinated care approach** adopted by SNELCAS, such as referrals to **specialist** and **multidisciplinary services** including physiotherapy, ME service and occupational therapy. Some patients highlighted that this support and efficiency for onward referral was more effective than previous attempts to address symptomology with a GP:

> *“It’s been like a one-stop shop where multi-disciplinary practice has again proven to work best for the patient."*
>
> *“Support and hope. Really useful to have one organisation with all the specialists in one place.”*
>
> *“Having dedicated specialist support that was also more accessible than GP.”*
>
> *“Having someone who would assess my case, instead of having the GP say 'if you have chest pain, go to the hospital' and the hospital saying 'if you have problems, go to your GP'”*
>
> *“The [SNELCAS] clinicians I spoke to really listened to my health issues and arranged for me to receive the necessary medical care and intervention that my GP had no interest in providing. I cannot thank SNELCAS enough for helping me through such a difficult time and providing solutions to health issues that should have been dealt with by my GP.”*
>
> *“SNELCAS has been able to ask for referrals to specific services based on my symptoms, when the GP has been much less clear on the way forward”*
>
> *“Chest physiotherapy sessions have been invaluable and I'm noticing such an improvement in my persistent cough and breathlessness by using the techniques practised in these appointments. “*

Respondents also appreciated **referrals to specific programmes**, both internally and externally provided e.g., 6-week self-management programme and social prescribing courses. External arts and exercise programmes, including the English National Opera (ENO) breathing programme, were particularly enjoyed by patients. Citizens Advice Bureau was also cited as a very useful source of support for some patients.

Theme 3. Practical tools and information

Access to information about long COVID and how certain strategies might help individual cases on their recovery journey were key. Having guidance when sourcing and accessing this information was also important for several patients who said that utilising this for their own **independent recovery** was a valuable output of SNELCAS:

> *“It’s has given me the tools to try and live a life without COVID [staff] have been fantastic”*

> *“Being offered a variety of treatments, resources and educational tools to aid my physical and mental health recovery. I especially enjoyed the sports for confidence and the lino printing course organised by SNELCAS. ENO sessions significantly improved my breathing techniques”*

> *"I can’t thank them enough for helping me through this intense experience and giving me back control over my health."*

> *“Information on illness and about how I could support my own recovery”*

> *"Understanding what was happening to me and how my health could be improved."*

> *“Self-help is crucial and [SNELCAS] has allowed me to do that. Information is power”*

The **Living With app** was enjoyed by many patients also, not only for access to information and courses, but also for regular contact with clinicians and peer support. Workshops and courses on coping techniques were highlighted by many as being especially valuable resources that patients could return to.

Theme 4. Personalised and patient-centred care

Patients appreciated individualised care that considered their **unique experiences and symptoms of long COVID**. **Regular check-ins** were also highlighted by many as being particularly useful and/or valuable, either via the app or telephone consultations. These **follow-ups** and check-ins were a key theme of the personalised care, and useful for patients who had previously felt unacknowledged by healthcare services:

> *“[SNELCAS] treated me as a whole person not just someone with long COVID”*

> *“The tailored treatment plan based on symptoms”*

> *“[SNELCAS] is the only NHS organisation that has offered or provided any support at all […] I feel that I have been left completely out in the cold, […] and the only people that are checking in on me are [SNELCAS] team.”*

> *“It is all so well organised, I can get in touch with the admin team by email, phone or app, they respond usually same day, loads of resources sent out by email.”*

Patients also emphasised the impact of staff on their recovery journeys and experiences of the service: Many patients felt “*listened to*”, “*cared for*”, “*reassured*”, “*at every stage, treated with dignity, respect and with good communication*”.

Theme 5. Community and shared experience

A very common theme alongside the importance of feeling heard by clinicians, was the value of being able to **share experiences and peer support** of long COVID and recovery with other SNELCAS patients. Connecting with others who shared similar experiences of long COVID reassured patients that they were not alone:

> *"Hearing other people's experiences with Long COVID. Feeling I'm not alone."*
>
> "Being able to share my feelings with others definitely made me feel not alone"
>
> *"Being referred to other agencies who brought me into a community of fellow LC recoverees, hearing their stories and recognising that our experiences have impacted us in different ways. Sharing information and being helped by others, as well as offering suggestions which have helped me"*

Patients cited **peer support groups**, ENO sessions and the Living With app as some of the ways they were able to engage and connect with others.

5.9. Qualitative feedback: How could patient experience be improved?

We asked all patients "What about your overall experience with SNELCAS could have been improved?" although many patients said that the service simply could not be improved, for others key themes indicate 4 important themes/areas for improvement, which came from 56% of all surveyed patients.

Theme 1. Communication: Regularity, consistency, and clarity

An overwhelming theme was the **lack of effective communication**, particularly the inconsistency of communication from SNELCAS and long periods of time without any communication from the service at all. Many patients who highlighted these issues said that they felt frustrated, "*alone*" and "*abandoned*" when they had been "*promised*" services or onward referrals, particularly when these were assured to occur within a certain timeframe but did not come to fruition. Indeed, many of the surveyed patients were still waiting to hear about onward referrals to other services and/or programmes and follow-up appointments. Overall, patients frequently mentioned delays, unclear updates, and poor follow-ups:

> *"Told I'll get an appointment next month, and despite chasing every month, and complaining, it's taken 11 months."*
>
> *"The initial delay in getting seen and getting the information regarding other support and partner agencies. The first 2 years were almost void of any positive input"*

> *“I felt it was very depressing I felt no support. They promised things that never came to pass”*
>
> *“Communication in general could have been a bit better. I had to wait a long time to hear about the [onward referral]. In the end, I chased it up with the clinic who said they had tried to contact me about them but hadn't been able to get through by phone. However, they could have left a voice message, emailed or messaged me through the app, which would have reduced my waiting time.”*
>
> *“It was galling after waiting for over 3 months for this and having missed out on my first referral because I had only just woken up when I got the call. It was galling to be told after a year that long COVID usually clears up after 2 years. I would have liked a more in person approach, as I didn't meet anyone until about 8 months into the programme”*

Some patients also said that **sufficient communication was necessary to allow patients to organise themselves** e.g., supporting them to attend appointments while managing their symptoms; feeling **forgetful and overwhelmed by information** was a primary concern for those with this symptom of long COVID:

> *“At first there were a lot of things offered which I found a bit overwhelming. My anxiety was taking a hit at the time and keeping track was a bit stressful. One of the big things I've been working on is pacing and that's really hard for me*
>
> *“Either I forgot that I was being referred to things or I was not told”*
>
> *“As I've been linked in with lots of services and programmes (that are incredibly helpful) it is a bit overwhelming to keep track of them all and remember to use them. It would be good to have a central portal to access everything through”*
>
> *“There were too many referrals all at once and it was really difficult to keep up with everything at once”*
>
> *“A lot of referrals came through at once and became difficult to coordinate and manage so many appointments and virtual meetings with my fatigue”*

Reminders were suggested a way to support patients to recall when their next appoint was due, who with, and the reason for the appointment itself. Outlining key dates at the time of initial appointment was also suggested as a strategy to keep patients informed and synchronised with their treatment.

Communication regarding **availability and points of access to offered services and programmes** were also highlighted as issues within the context of communication. Some patients were unsure of what programmes were available, if they were eligible to participate, and how to enrol or self-refer:

> *“I haven’t been contacted in the 2 months since assessment or been referred to any other programmes e.g., yoga, Pilates, not sure how I access these services”*

A few patients also pointed to the ability of SNELCAS to **support onward referrals and facilitate progression of diagnostic testing** from other services e.g., tests ordered by GPs, or specialist referrals that have not been chased and increased overall waiting time as a result:

> *“My only criticism is that my GP did not do all the tests that were required before my referral to SNELCAS, and SNELCAS did not follow that up and insist the GP did them or arrange the tests themselves. It appears I may have had a low-grade chest infection for two years”*

> *“I am still waiting on physio/Fitbit which has been over 6 months. I have been promised twice but no contact. ENO not completed due to me having SVT and until that is sorted, [ENO provider] will not help”*

> *“None of them communicate... it makes coordinated care extremely difficult."*

A few patients felt that their appointments were **rushed**, that they were either **discharged before clinically appropriate**, or informed that discharge was imminent despite the patient not feeling ready, and/or experienced an uncomfortable reception from SNELCAS staff:

> *“Appointments often feel rushed, [staff] seem keen to discharge you when you're still unwell”*

> *“At my last appointment I was asked if I was ready to be discharged from the service, when I said no, I still suffer from the effects of long COVID. I was told we can’t keep you on the books for ever! I felt very letdown and alone…”*

> *“I felt like my condition, my thoughts and opinions were just brushed under the carpet, and I felt like no one truly cared about how I was feeling and how to properly help me get better. The only thing they were really prepared to do was refer me to an occupational therapist but gave me absolutely no reason why”*

Theme 2. Personalised and patient-centred care

Although many patients praised the personalised and patient-centred care they received while engaged with SNELCAS, other patients did *not* have such positive experiences.

Face-to-face and/or one-to-one contact was also viewed by patients as crucial to feel that they were heard and that their treatment was personalised to their clinical needs. The remote approach sometimes used by SNELCAS e.g., telephone consultations, appear to remove a key component of personalised care for patients:

> *“The lack of in person, personal connection - whilst very appreciative of the support I received (I know not everyone in UK is so fortunate), I have felt so isolated and abandoned by the medical side of the health service”*

> *“[remote appointments] Didn't feel like a dialogue, not much follow up. I did not have a single face to face meeting (or the option to meet that way)”*

> *“All I have had from SNELCAS is the regular calls where they ask a series of questions, and those questions can be quite vague, and don’t give the picture at all”*

> *“More opportunities to meet face-to-face, some conversations distressing and sensitive where I got upset due to big life changes.”*

Patients may also feel that more face-to-face and/or one-to-one appointments would provide **reassurance that they had not been forgotten** about and/or discharged during periods of waiting time between appointments and referrals.

Most patients who highlighted the issue of **information sharing** e.g., between systems, and healthcare professionals having access to patient notes, said that they felt frustrated when they regularly had to “repeat” themselves. Often this led to feelings of not being listened to, or that healthcare professionals were not fully engaged with their individual case. Understanding the personal, lived experience of patients is important for how well they feel cared for and treated.

> *“I found in follow-up appointments; I had to repeat the same information I had provided in my initial assessment. The clinician appeared not to have read my notes and so made suggestions for referrals that weren't relevant to me”*

> *“I wish they could access my medical records […], all my notes etc.”*

> *"I had to repeat the same information I had provided in my initial assessment."*

Patients would like SNELCAS staff to be more **understanding and accommodating of their individual needs and circumstances**, rather than to take a generalised approach. Although notably one of the key approaches of SNELCAs praised by service users was its ability to provide patient-focused, individualised care. This feedback highlights that while this is working well for some patients, there are others who are not feeling these benefits:

> *“There should be more of a focus on empowerment and care plans should be based on what service users identify their support needs to be and not on what the service is able to offer. Finally, reduce inappropriate referrals - it's disempowering for service users and is a waste of resources”*

> *“I wish there was something or those whose recovery journey was more protracted”*

Theme 3. Accessibility and adaptability of offerings

Several patients agreed on the **issue of location**. Many of the offerings provided by SNELCAS are Ipswich-based, which is difficult for those who live further afield and may have difficulty driving due to symptoms of long COVID. A greater number of meetings was also suggested to ensure that more people could attend:

> *"Everything that I was offered, apart from a few online things, which are too tiring so couldn't partake, was in Suffolk, Ipswich or further beyond. The only thing in Colchester […] was the Sport for Confidence. Although this was helpful to a degree, I feel I have missed out greatly on things on offer due to not being well enough to travel to Ipswich regularly. The craft sessions that were in Colchester were very sparse and then stopped altogether. If it wasn't for Liz referring me to the craft group in Ipswich, I would not have had any contact, however sporadically, with others with Long COVID that understood"*
>
> *"I found getting the information about activities local to me was tricky, given that I was too tired to drive, participate and drive home"*
>
> *"Services available closer to home and activities that could be accessed for those that have to work"*
>
> *"The 6-week program was only on a Wednesday to which I work and therefore could not attend the program. This is very disappointing, more dates need to be available"*

Theme 4. Peer support and group opportunities

Peer support was one of the favourable attributes of SNELCAS, but it appears that some patients are not offered opportunities to engage with peer support activities:

> *"More links with others with the same condition More information about changes in understanding of condition as it develops for post patients as still living with condition after accessing the service"*
>
> *"I think the additional resource of a local support group where people can interact with others in the same position and at a similar place of recovery would be a positive step for people in recovery"*

5.10. Qualitative patient feedback: Summary

Patients highlighted several aspects of SNELCAS as valuable to their experience. Emotional support and empathy from specialists who understood long COVID were frequently praised, with patients feeling validated, listened to, and reassured. Many appreciated the service's coordinated care, including referrals to specialists, therapy, and helpful programmes such as the ENO breathing course. These interventions were often described as more effective than prior attempts to address their symptoms through GPs. Practical tools and information provided by SNELCAS helped patients to understand their condition and take steps toward recovery, and resources like the Living With app and external coping workshops were particularly appreciated. Patients valued personalised care tailored to their unique symptoms, with regular check-ins offering reassurance and support. The sense of community fostered by SNELCAS was another key strength, where peer support through group activities and apps helped patients feel less isolated by connecting them with others sharing similar experiences. These shared connections offered emotional relief and practical advice. Overall, SNELCAS was described as a vital resource, providing understanding, guidance, and a sense of connection for those navigating the challenges of long COVID, and many patients were very appreciative of SNELCAS staff.

In terms of areas for improvement, communication was a major concern, with many reporting delays, inconsistent updates, and poor follow-ups that left them feeling frustrated and unsupported. Suggestions included regular updates, appointment reminders, and clearer information about available services. Some patients also found the care impersonal, particularly with remote consultations, and felt frustrated by having to repeat their information due to poor record-sharing (despite many understandings this to be an inherent issue). They recommended more face-to-face appointments and tailored care plans. Accessibility was also an issue, as many services were located far away or scheduled at inconvenient times, making them difficult to attend; patients suggested offering more local and flexible options. While peer support was valued, not all patients had opportunities to engage with groups.

5.11. Patient perceived impact of internal and external support services

The present section outlines patient feedback for the four key offerings, including those hosted internally by SNELCAS and those funded by but provided externally to SNELCAS.

For surveyed patients who had engaged with each of the services below, we asked whether their experience of the service (a) was useful, (b) provided a positive impact on their recovery journey, and (c) was comfortable enough that they felt able to engage with the support offered.

Citizens Advice Bureau

Eighty percent* of patients asked about their engagement with Citizens Advice Bureau (CAB) said that it was useful, half said that the service had a positive impact on their recovery journey, and 60% said that they felt comfortable and able to engage with the support received through CAB.

For most patients, financial support provided by CAB was the leading, most helpful aid. Very few patients gave suggestions for improving the service within the context of long COVID support, and emphasised the support and usefulness to them personally, although one patient did note that more advice regarding the availability of social prescribing offerings would have been desired.

> *“They guided me step-by-step on how to complete my blue badge application, they followed up on me regularly and seemed genuinely interested in my welfare, and in me getting the correct assistance.”*
>
> *“Kate at CAB was so supportive. She helped me get PIP and put me in contact with Marta Williamson at the council who was very supportive. CAB went above and beyond to help me”*
>
> *“[Patient would like] more information about social prescribing e.g. work coaches, access to charity MH support etc - knowing what is out there”*

*Note that due to a technical error, unfortunately only 5% of *all* surveyed patients were asked about CAB.

Six-week self-management group

Sixty-four percent of all surveyed patients reported having attended the 6-week self-management group, hosted virtually by SNELCAS.

Among patients who had engaged with the programme, 87% found the support programme provided useful information, 69% reported a positive impact on their recovery, 96% felt treated with dignity and respect, and 82% were comfortable engaging in group activities. Additionally, 85% were satisfied with the programme's virtual format. A breakdown of responses is shown in Figure 9.

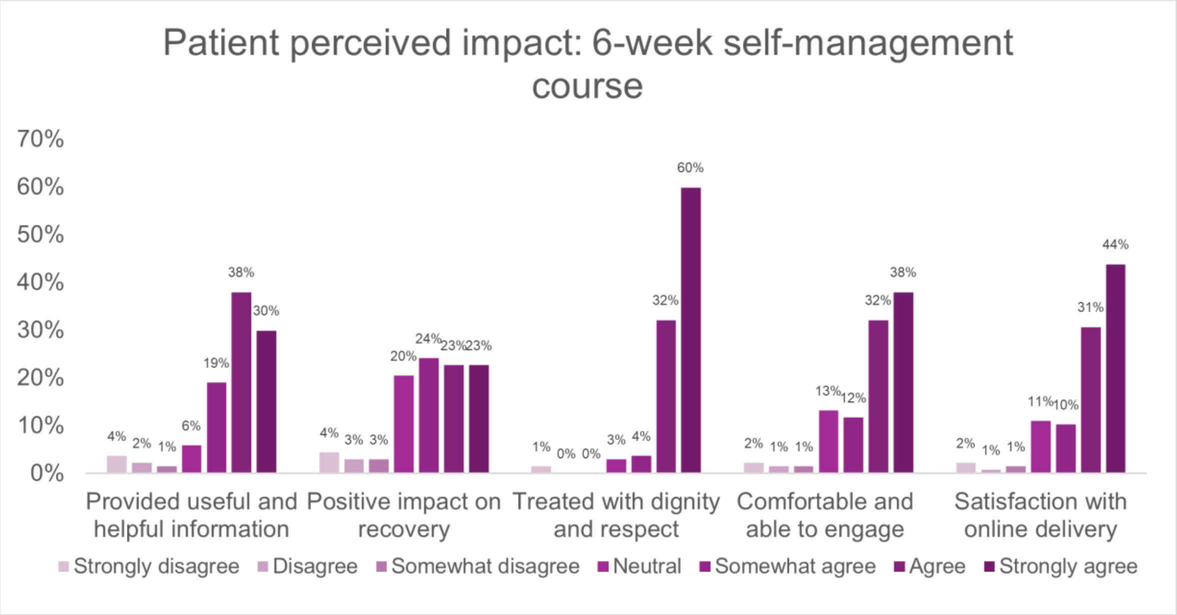

Figure 9. A breakdown of responses (from Strongly disagree to Strongly agree) for each of the 5 themes including whether the programme provided helpful and useful information, made a perceived positive impact on the patient’s recovery journey, if the patient was treated with dignity and respect, whether they felt comfortable to engage with its offerings, and satisfaction with the virtual, online platform on which it was hosted.

When asked what worked especially well about the programme, an overwhelming theme highlighted by almost all patients was the peer support offered by the group sessions. **Sessions reassured patients that they were not alone and validated their experiences and symptoms** of long COVID, helping them to feel less isolated and share advice for symptom management:

> *"It was good to find out that I wasn't alone in some of my symptoms as I had felt like I was going mad"*
>
> *"It helped me to hear other people with exactly the same symptoms as I had. The thing with long COVID is that you start to think you are making it up or going crazy. It is such an unusual set of symptoms and there are so many that I understand how it is easy to convince yourself that you should be trying a bit harder or that you may be imagining it all. Hearing other people describe the confusion, the cognitive impairment, the crushing fatigue, and the post exertional malaise helped me to see that I was not alone, I was not making it up, and while there was nothing that anyone could really suggest to help me, at least I wasn't alone"*
>
> *Enabled me to think about how I was living and how and what I was doing and what I could do more to help myself more.*
>
> *"It was lovely to know I wasn't going mad and that there were others that could articulate how I felt better than me."*

Validation of recognition of long COVID is especially important for patients. This was a key theme identified previously when patients were asked about their overall experience of the service, and their **relief from self-doubt**.

Information sharing and learning **self-management strategies** was also crucial for patients to feel a sense of autonomy and independence over their recovery. Participants valued practical tools and actionable advice, such as the 60:20 fatigue management strategy and tips on pacing, boom/bust cycles, and energy management, to help manage fatigue, sleep, and other symptoms.

Finally, although many patients did not enjoy the virtual delivery of the programme (see below), a few did highlight the benefits of **remote accessibility** afforded by the online platform:

> *"Being able to join in…however I was feeling…laying down in bed…not having to get up and go out"*
>
> *"It was helpful having an online course, so no traveling was involved"*

When asked **what could be improved about the 6-week self management programme**, feedback was mixed but clustered around the theme of the symptomology of long COVID that would often impede (1) engagement with the programme, and/or (2) relevance for the patient, and unnecessary energy expenditure as a result. Several patients explained that due to the idiosyncratic nature of long COVID, it was often tiring for patients to attend sessions that were not necessarily directly useful to them. Acknowledging the different extents that others' experienced long COVID, some said that it was "*disheartening*" to attend sessions with others who had not recovered in a very long time. Patients suggests that because "*not all patients need all 6-week topics*", splitting sessions into severity and/or needs would mean that those attending could allocate their attention to relevant content without worrying about the fatigue that would follow "*longer than necessary*" attention. Smaller group sizes would also allow for "*individual advice for personal circumstances*", and the "*gentle discouragement of some members occupying much of the time with long winded anecdotes",* and group discussions between patients who experience the similar kind and severity of symptoms:

> *"Because it is designed to be for a group and help as many people as possible, even though that is good, it means that specific tailoring of support to different people isn't really there, which is the issue, because everyone is different so everyone will have different ways of managing Long COVID."*
>
> *"It would have been better if we had had more time to ask questions and discuss the content with the clinician 'live'. Because of the length of each session, there often wasn't adequate time for this, especially as there were often 70 or more service users attending each group. It would also have been helpful to have a peer-support section built-in at the end of each session for us to share ideas and strategies."*
>
> *"It is a lot of information to take in and act on. Too much for someone who is fatigued and brain fogged."*
>
> *"All sessions were too much about information being provided via video which we could have watched in our own time. This meant there was hardly any time for questions or for peer-to-peer conversations, which would have been very useful"*
>
> *"At the time I was having great trouble with concentration and memory. I found it very difficult listening to talks by experts. It seemed quite technical at times. I thought it would be more interactive"*

Finally, the online platform, while acknowledged as more accessible and accommodating for patients, was difficult for many who **struggled with screen use** and maintaining consistent attention due to **brain fog**. Recordings of sessions were suggested as useful for those who could not attend due to symptoms, or to revisit at a future time when they needed to refresh their memory:

> *"I found it hard to engage via teams or zoom. This is because one of my specific symptoms is a difficulty with screen use, and while I can engage if I'm not looking, or not have the camera on, it does detract from the experience a bit. If I had the camera on or focusing for PowerPoint presentations et cetera, then I would get nauseous and dizzy very quickly."*
>
> *"Online hurts my head, brings on migraines and is just not very personable"*

> *“I didn't like Zoom - like many others with long COVID, I found it overstimulating - but at least it was convenient, and I could do it from home”*
>
> *“Sometimes having Teams chat to try to follow plus someone talking could be a little overwhelming (suffering at the time with difficulty multi-tasking)”*
>
> *“Being able to do it at my own pace would have been good. If you don't attend, they'll discharge you, so I made my symptoms flare because I had to go live. I also had to attend a session on breathlessness, a symptom I don't experience”*

Kiactiv

Half (48%) of all surveyed patients had engaged with KiActiv. Feedback was relatively mixed. Of those that had used the service, 62% agreed that they were given useful and helpful information, there was not a discernible impact of the service on patients’ recovery, the majority (94%) felt that they were treated with dignity and respect, and 66% felt comfortable and able to engage with KiActiv’s offerings. A breakdown of responses are shown in Figure 10.

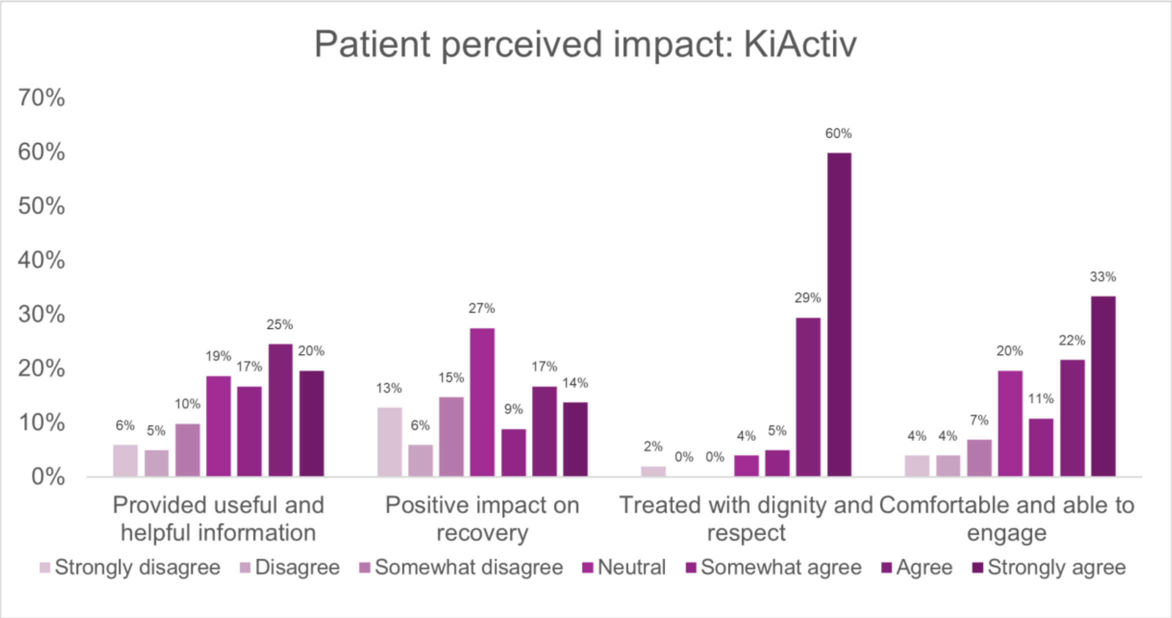

Figure 10. A breakdown of responses (from Strongly disagree to Strongly agree) for each of the 4 themes including whether the programme provided helpful and useful information, made a perceived positive impact on the patient’s recovery journey, if the patient was treated with dignity and respect, and whether they felt comfortable to engage with its offerings.

When asked about what they particularly enjoyed about KiActiv, many patients reported appreciation of the **support and mentorship** of the programme. Regular check-ins and support from mentors or coaches were described as helpful, and staff as kind, and motivating. Personalised feedback and guidance were commonly highlighted as valuable. Having **self-awareness of activity and energy expenditure** was also an empowering outcome for many; the ability to track activity levels and correlate them with symptoms helped some participants better understand their energy usage, avoid boom-and-bust cycles, plan for rest, and symptom validation:

> *"[KiActiv] helped me understand more about Boom and Bust. and I could see more about energy use and how to manage that.*
>
> *"The course leaders were absolutely excellent - very friendly, engaging and supportive. The small group worked well, and we were all supportive of each other. The techniques and exercises, as well as the online self-management course, I am sure have helped me to return to much as I was before having COVID (despite that process taking a little over a year)"*
>
> *"Being able to chart and understand ebbs and flows in my energy levels"*
>
> *"It made me think I was not in fact pretending or being dramatic."*

When asked how their experience of KiActiv could be improved, patients' feedback was largely focused on **technology and usability issues.** Issues with the watch included malfunctioning, poor usability, difficulty navigating buttons, and lack of functionality (e.g., no heart rate tracking, sleep tracking, or waterproof design). Concerns regarding app and dashboard usability also included the issue of an overwhelming interface that wasn't user-friendly, a lack of optimisation for mobile, and difficulty with data syncing. Patients suggested that an upgrade of the device itself, dashboard and interface simplification and the incorporation of more advanced health metrics would all improve the experience. Similarly, to the 6-week programme, cognitive overload was a concern for many, where "*the vast amount of data entry each day was a massive deterrent*", without clear instructions or steps that were accessible to those with brain fog, and little application for long COVID-specific symptoms:

> *"For me I think [KiActiv] came too soon - still very limited in what I can do physically so the ability to assess what adding extra activities may have didn't seem very relevant. The dashboard and other info on the website seemed overly complicated - the stats and data from my own smart watch seemed easier to understand. It would be good if the watch would sync data automatically rather than having to remember to do it manually every day."*
>
> *"I have some cognitive impairment and noticeable memory problems since Long COVID. This meant I was unfortunately not ready for my first session as I had forgotten/didn't understand what was required of me as preparation. I would suggest a step-by-step guide regarding synching and reminders to do so before the first session. I also had trouble finding the programme and thought I was supposed to access it via the app. Again, for those of us who struggle to process instructions, I would like to suggest a very simple guide in plain English to help. Apart from these proposals, I think it is an excellent programme."*

Sport for Confidence

Twenty-three percent of all surveyed patients reported having engaged with the Sport for Confidence programme.

Of these patients, 82% said that the programme provided helpful and useful information. While around a third of patients found it to be very beneficial for their recovery, feedback was relatively mixed. Ninety-five percent of patients said that they were treated with dignity and respect, and 83% felt comfortable and able to engage with the programme's offerings. A breakdown of responses is shown in Figure 11.

When asked what they particularly enjoyed about the programme, "*comradery*" and **peer support** were key themes in the feedback, as well as **one-to-one support from staff** who helped patients to feel empowered, encouraged and motivated. The opportunity for face-to-face support was also a positive feature of the programme, although some patients highlighted that this befit could really only be enjoyed by those who were still able to travel despite having long COVID. Educational sessions were the second most frequently mentioned benefit of the programme, where patients particularly enjoyed the mix of theoretical and practical skills learned, and the variety of information covered e.g., diet, sleep, exercise:

> *"[Sport for Confidence] is face-to-face which in itself is a huge positive for those of us who are well enough to attend in person. The peer support aspect is therapeutic and has definitely had a positive impact on my psychological wellbeing in terms of feeling less isolated and alone. I think that the fact it takes place in a non-clinical setting is also a subtle way to make those of us with Long COVID feel more empowered as it helps flatten the usual patient-clinician power structures in place"*

> *"Went over a lot of info already given but I found the reminder very useful and there was a lot of new stuff too. Great to be face to face and lots of time to ask questions and get very specific advice for your own unique struggles. Have finished the theory part and now onto the physical part and really enjoying it. Feel really confident that I'll be able to work out a base line for my energy levels and then start trying to gradually build on that and start to recover some of the stamina etc that I have lost through long COVID."*

When asked **what could have improved their experience** of the programme, many patients expressed a need for more local sessions, particularly in areas like West Suffolk and Bury St Edmunds, to reduce travel strain. Session length and structure were also a concern, with suggestions for longer sessions, better scheduling to avoid conflicts with loud activities, and more flexible timing options. A key theme was the balance between theory and physical activity, with calls for less repetition from online courses, more practical exercises, and a better integration of theory and practice. Patients with long-term conditions emphasised the need for gradual exercise progression to prevent Post-Exertional Malaise (PEM) and better monitoring of activity impact. Communication and presentation improvements were also suggested, including simplifying PowerPoint slides, providing electronic copies, ensuring clearer session updates, and having trainers speak more clearly and slowly. Additionally, greater awareness among GPs could improve referrals and accessibility. Finally, participants recommended additional support, such as gym or swimming vouchers, and extending the programme beyond six weeks for sustained benefits.

> *“Communication about change in times of sessions, there was none. Greater consistency in sessions, especially with who was leading the sessions, and their value. No forwarding of information of information after an information session, although it was promised. The course at Stowmarket Leisure Centre was a great disappointment.”*
>
> *“A variety of days and times. offering programme of longer than 6 week sessions.”*
>
> *“Power point presentation had too much text on it and could have done with being simplified. It would have been helpful to have the PowerPoint sent to us electronically so we could look at it in our own time. Would be better if the person relaying the content could speak more loudly and especially more slowly - to compensate for minds that are operating at less-than-optimum capacity!”*

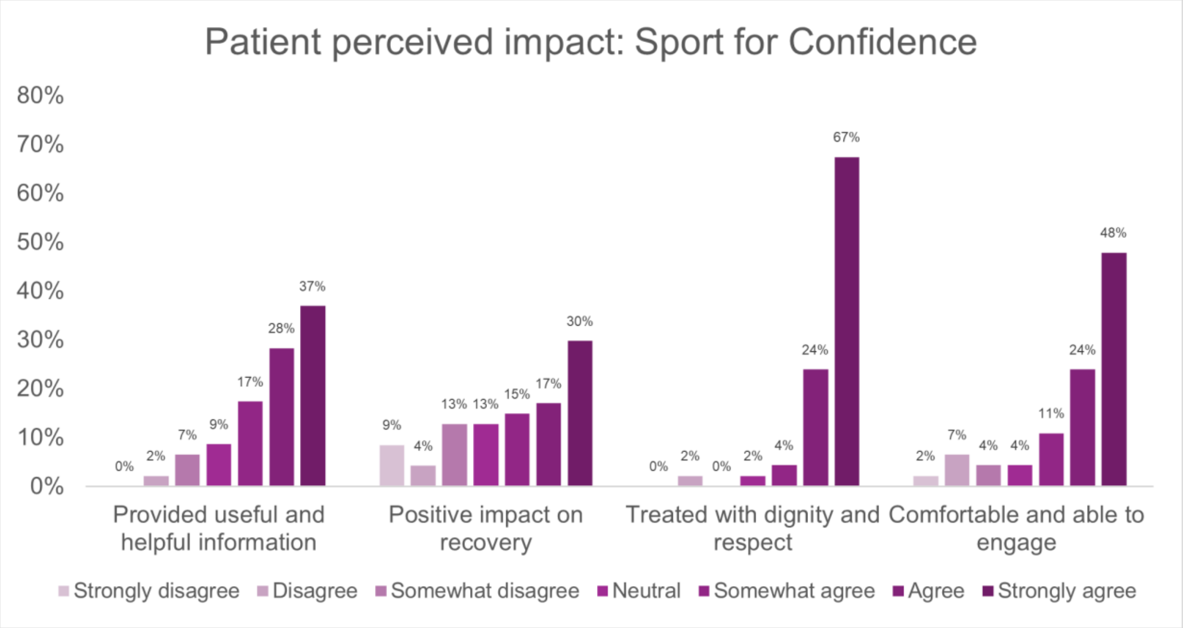

Figure 11. A breakdown of responses (from Strongly disagree to Strongly agree) for each of the 4 themes including whether the programme provided helpful and useful information, made a perceived positive impact on the patient’s recovery journey, if the patient was treated with dignity and respect, and whether they felt comfortable to engage with its offerings.

Living With mobile phone application

Seventy-five percent of all surveyed patients reporting having used the Living With mobile phone application.

Of these patients, the majority (77%) agreed that the app provided useful and helpful information, most were either neutral (22%) or in a degree of agreement that using the app made a positive impact on their recovery journey (58%), and the majority

(75%) said that it was intuitive and easy to use. A breakdown of survey responses is shown in Figure 12.

When asked what they particularly enjoyed about the Living With application, **symptom tracking and self-monitoring** was a leading theme. Many users appreciated the ability to track their symptoms over time, and the regular questionnaires that would help them to see and track their changes. Graphical daily displays of progress were enjoyed by many, as well as the diary function. Reminders to take medications were appreciated, particularly for lessening the burden on users. Knowing that they could use the application to reach out to healthcare professionals and SNELCAS staff was a reassurance to patients. Receiving responses without needing a phone call was convenient, although some users did feel that there was a lack of feedback on their input (see below).

> *"I like the ability to track my symptoms, I like the questionnaires so I can see how there has been any improvement or not overtime, and I like the information that is available for me to access at my own pace. I also liked the ability to send a message and have a member of the team respond without having to go through a long-drawn-out telephone call"*
>
> *"It was good to be able to send results through quickly and easily and to be able to contact a member of the team"*
>
> *"The constant upload of new information and videos. Some days you just cannot watch anything but very easy to catch up when you are in the mood"*
>
> *"The information was provided in a very clear and approachable manner. I enjoyed reading the advice and found it reassuring that the narrative put into words what I was experiencing but struggled to express".*
>
> *"Diary function particularly valuable in identifying, understanding and managing fatigue levels, including being able to share with my employer to help support my attendance at work"*

When asked **what about the application could be improved**, many users said that they found the content to be **overwhelming**. Indeed, this is a consistent theme in patient feedback, where the "overloading" of information, even in terms of how it is displayed or accessed, can feel overwhelming for those who are struggling with brain fog and information processing. Themes of overwhelm were very common:

> *"It asks me to read an overwhelming amount of information for each assessment form. This became so stressful that I've stopped keeping up with filling out the assessment forms on it"*
>
> *"The Living with app did not work for me. I felt pressured by it to set goals, when I couldn't keep up it made things worse. At this time, I could not concentrate or hardly string a sentence together. I closed it down and forgot about it."*

> *"Less complicated, [patient] found it overwhelming. It was too much to take in and exhaustive and have not used it recently"*
>
> *"Far too much repetitive information. Far too Many repetitive questionnaires. I found it induced anxiety and stopped using it after a month or two"*

It seems to be that for many individuals, the app works very well and supports patients on their recovery journey. However, for those that are living with extreme cognitive difficulties and brain fog, the app could become more of a hindrance than a support. For those that have **difficulty engaging with screens**, the app is unlikely to provide a supportive function. Several patients also noted that while the app facilitates communication between the user and SNECLAS staff, **the lack of face-to-face or one-to-one communication** can be emphasised. Relatedly, patients also highlighted that often when they would log negative symptoms of a decline in their health, often these updates would not be registered or fed back by a clinician, which appeared to leave some patients feeling alone:

> *"I also found it difficult to score how I am feeling - when in clinic in person I was advised that I was consistently under scoring how much my symptoms affected my daily life for example"*
>
> *"Because it is so repetitive it loses its impact. Feedback on responses would be helpful, but I realise this is time consuming"*
>
> *"More interaction from medical staff e.g. consultants checking in on patients".*
>
> *"I haven't found it easy to use on a regular basis […] I find it much easier to interact with a person face to face."*
>
> *"I felt as though I was being processed rather than cared for, kept at arm's length and simply given information that I could find out myself online. There was a lack of bespoke expertise."*
>
> *"At least some feedback would help"*
>
> *"Nothing came back from consultants. It would also be great to be able to stay connected via the app with fellow recovers after the 6 weeks but that was not possible"*

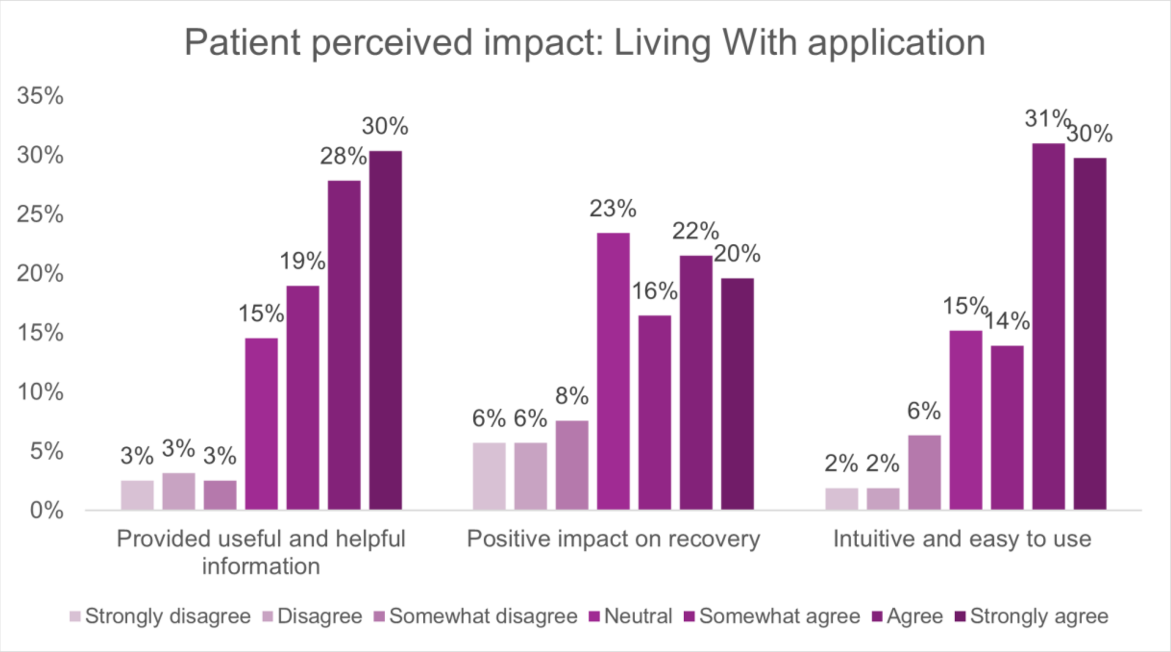

Figure 12. A breakdown of responses (from Strongly disagree to Strongly agree) for each of the 3 themes including whether the application provided helpful and useful information, made a perceived positive impact on the patient's recovery journey, and if it was intuitive and easy to use.

Engagement with other activities through SNELCAS

Patients were asked whether they had participated with any other activities through their engagement with SNELCAS. Figure 13 shows that Suffolk Mind and ENO were two popular offerings, followed by Yoga and Creative Health e.g., Cohere Arts. Notably, a small number of patients did highlight that they had expected to be referred to external services but were yet to receive any information:

> *"I can't remember but have known of some but I haven't joined many as don't hear no more from long vivid"*
>
> *"I was told I would be invited to join an art group but I never was. Not that I would have gone. I didn't really want to join any groups......."*

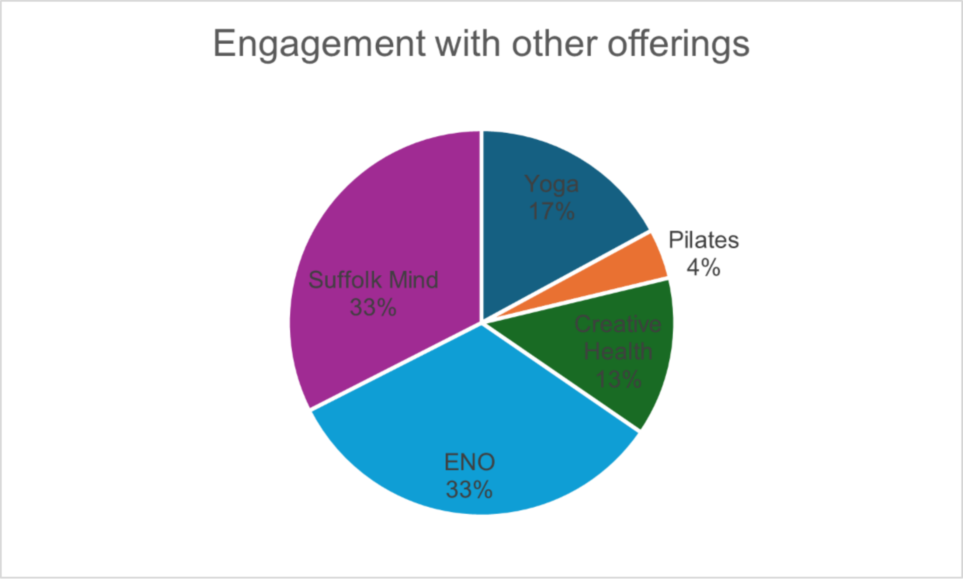

Figure 13. Proportions of surveyed patients who reported having engaged with external programmes recommended and funded by SNELCAS.

6. Service staff feedback

Seven staff members completed the anonymous online survey, including 3 nurses, 2 clinical care coordinators (senior nurses), 1 occupational therapist and 1 administrator. Four staff members were based at East Suffolk, 1 at West Suffolk, none from Northeast Essex, 1 at Constantine House in Ipswich, and 1 covering both East and West Suffolk sites.

Surveys constituted items addressing 6 themes: (1) the referral process, (2) administration, (3) collaborative working, (4) communication, (5) perceived patient experience, and (6) support for staff. Survey items were both Likert scale statement agreement ratings and free-text-response questions.

The referral process

All surveyed staff either strongly or partially agree that referring patients to onward diagnostic services (e.g., blood tests, scanning, etc.) work effectively. Onward patient referrals to subspecialities are also seen to work effectively (e.g., speech and language therapy, ear nose and throat, respiratory, cardiology), as are referrals to outpatient clinics (e.g., mental health). All staff also agree that patient referrals to external services work effectively (e.g., Sport for Confidence, Suffolk Wellbeing, Therapy For You etc.).

Barriers specific to internal and external referrals include referral strategies, variable referral criteria between geographic locations, and "*very limited services for patients that cannot access IT*":

> *"There are different ways to refer depending on which service we are referring to... this can be a little confusing e: some referrals are on SYSTEM ONE, others accessed via websites etc so need to make sure we know the referral process for each service"*

Service staff suggested that barriers could be overcome by placing all referral forms on SYSTEM ONE for a central point of access, updating the referral criteria regularly and consistently across locations, advanced nurse practitioner training and face-to-face courses, and requested investigations that can be reviewed at multidisciplinary team meetings.

Administrative support

All SNELCAS staff agreed that the service is equipped with sufficient administrative support to run effectively, and that administrative staff can access all patient information they require.

Most respondents did not highlight any barriers to administration, besides two staff members who both reported that surgery and services independently use other electronic record and operations systems (e.g., SYSTEM ONE). One staff member suggested that dedicated SYSTEM ONE training could facilitative effective administration at SNELCAS.

Collaborative working

Most (85%) of surveyed SNELCAS staff agreed that they were able to work collaboratively to fulfil their duties within their team, and one individual who did not. Eighty-five percent also agreed that were able to support each other, compared to one individual, again, who did not.

When asked whether there were any significant barriers relating to communication and support in the team, most respondents omitted a response. One respondent commented that hybrid working can be a barrier due to virtual meetings and the reliance of individual staff members to prioritise communication, and another commented that timing of meetings can be a barrier. Suggestions to mitigate these barriers included: regular check ins between staff, transparency between staff, and an awareness of annual leave and absence. Keeping cameras on during virtual meetings to show willingness to engage and be present. Furthermore, a suggestion to change timings of meetings, especially 8:30am meetings may reduce barriers to communication to change timings of meetings, especially 8:30am meetings may reduce barriers to communication to change timings of meetings, especially 8:30am meetings may reduce barriers to communication.

Communication between SNELCAS and referring GP practices

Most (85%) of surveyed SNELCAS staff said that there is good communication between SNELCAS sites (e.g., East/West Suffolk, NE Essex, Constantine House etc.), and 14% did not. Around two thirds (57%) believe that there is good communication between SNELCAS and referring GP practices, and 43% were neutral regarding this question.

When asked about significant barriers to communication between SNELCAS and referring GP practices, most omitted a response. Two respondents suggested that a lack of understanding and awareness of GP practices is a barrier to communication, with one respondent commenting that some practices are more aware of long COVID than others, leading to inconsistent referral rates:

> *“Some surgeries are more aware of long COVID than others, therefore referral rates differ a lot between surgeries. Would be great to get everyone on the same page and encourage communication between GP's and the service”*

Strategies to improve communication generally centred around the topic of outreach to improve awareness among referring GPs:

> *“More comms from our service to Practice managers, to visit surgeries, talk to the GP's/Practice nurses, maybe ask to be included in their group meetings*

> *once in a while - join their teams' meetings at the end etc to promote the service."*

Patient experience according to service staff

All surveyed SNELCAS staff were confident to some degree in their knowledge of what happens to the patient outside of their role and agreed that referred patients were seen quickly. All also agreed, to some degree, that SNELCAS patients are able to receive the correct care they need, in a timely manner, and that SNELCAS sites are physically accessible to patients. Again, all respondents agreed, to some extent, that patients leave their appointment(s) knowing what the next steps will be, and 100% of SNELCAS staff strongly agreed with the statement "I believe that patients feel supported throughout their journey".

Three staff members commented that (1) patients do not always receive the same advice and/or service referrals as others and (2) language barriers that can impact patient experience. One respondent also highlighted that clinics should ideally be ground-floor, particularly as able-bodied patients may struggle with breathlessness. commented on the location of clinic within a practice, as upstairs clinic can be a barrier, particularly if breathlessness is present:

> *"We need to make sure we are providing the same advice/service to all our patients. Collectively we need to be on the same page, to ensure all patients are being supported equally."*
>
> *"Patients in the West have less available to them"*

Staff suggested a collective approach to answering queries and discussions with multidisciplinary team meetings would ensure that correct information is being delivered, and that correct steps and instructions are followed appropriately. Another member of staff suggested that more face-to-face support could be useful for patients in locations where there are fewer services available to them.

Support for staff

All surveyed SNELCAS staff felt that they could access the support and resources required to do their job well. While most (86%) respondents reported that they felt satisfied in their current role, and one individual partially disagreed. Again, 85% of respondents agreed that their team was a positive environment, and one individual was neutral regarding this question.

When asked about barriers to staff support, most respondents omitted a response. However, one respondent commented the challenging nature of virtual team meetings in terms of engagement and connection, and another implied that the permanency of their role was of concern:

> *“Sometimes I find it challenging in team meetings to see cameras and mics off. Because we are communicating virtually, this highlights the need to engage even more so than if we were all in the same room together. A visual presence is important even when we are discussing someone else's patient. It shows the team a willingness to listen, engage and offer opinion/support if and when needed. Cameras and mic off literally puts a barrier of communication up between that member of staff and the wider team.”*
>
> *“[respondent] have concerns over ongoing role”*
>
> *“I would love to have more face-to-face training/staff meet ups. I think this would really help with staff cohesion and bring us out from behind the screen to interact with each other in person”*

Suggestions included offering more training opportunities for staff, face-to-face engagement, and promoting obvious participation during virtual meetings.

Summary

Anonymous survey findings show that SNELCAS performs well in several areas but also highlights some areas for improvement. Referral processes are effective for diagnostics, subspecialties, and external services, though variability in criteria and navigation challenges between systems were noted by staff. Communication between SNELCAS sites is effective, but outreach to GP practices is a separate matter that is needed to improve understanding and referral consistency. Suggestions for internal consistency include centralising forms, updating criteria, and improved communication at team meetings. Administrative support is well-regarded, but training on SYSTEM ONE could address issues with multiple record systems. Team collaboration is generally strong, but hybrid working and virtual meeting practices, such as lack of engagement, were identified as barriers. Staff feel that patient care is timely and appropriate, though inconsistencies in advice in terms of onward referrals and services offered were noted, language barriers, and accessibility issues (e.g., upstairs clinics) were raised. Multidisciplinary discussions and more face-to-face support in underserved areas were recommended. While SNELCAS is effective in key areas, addressing inconsistencies in referrals, communication, and support will improve the service further.

SNELCAS patient peer support group: Findings from a dyadic interview

We conducted a dyadic interview with two SNELCAS service users who had previously attended at least one of the online peer-support group sessions. The dyadic interview took place over a single session, online

Sessions are offered to SNELCAS patients following completion of the 6-week self-management programme. Sessions are hosted online, organised and hosted by a SNELCAS member of staff who also has lived experience of long COVID.

From our dyadic interview with two attendees of the online peer-support group, we identified 4 core themes, outlined below:

6.1. Theme 1. Validation and understanding

The group leader's lived experience with long COVID fosters empathy, trust, and validation among participants. This contrasts with other NHS-led initiatives run by clinical experts without personal experience, which feel less relatable, and reassures patients about the relevance of the clinical advice they receive.

Similarly, to the 6-week self-management programme, patients feel that an invaluable feature of the peer support group is the space it provides for collective sharing of experiences, reduces feelings of self-doubt and isolation. This is particularly important not just for sharing experiences of symptoms in isolation, but their impact on every other aspect of individuals lives:

> *"I think [having the group organised by someone who has long COVID themselves] is really beneficial, not least because for me, the principal benefit of self-management and also peer group is understanding what is the shared experience and result of long COVID, and what's peculiar to you, because [long COVID] is very isolating and also because it's a fluctuating condition, you can almost end up doubting yourself or feeling like you're a fraud […] it made me realise that [idiosyncratic symptoms] is something that I should not only do for myself, but be aware of for anyone else that presents with long COVID"*

> *"there's also that understanding of what is common experience from people that because they've experienced it, including person coordinating it, y'know, just that you're believed because even your friends and work colleagues […] They don't expect it or see it as a potentially ongoing situation and ongoing changes*

> *"Because [effects of long COVID] are very practically rooted. It's the, you know, it's the day-to-day reality of it and the impact of your symptoms, you know, there's a lot of shared experience and issues"*

Patients also indicated that the size of group sessions was ideal given the spread and diversity of symptoms, where a balance had been found between supporting those with perhaps the more common symptoms of long COVID versus there being enough shared experience for minorities of individuals with less likely symptomology:

> *“Even for things that aren't necessarily as widely spread […] like for example, appetite and taste […] when we have these sessions, it seems like that's a minority of people that have that issue. But even there's enough of them, even in the sessions that when those issues are raised, they're able to get peer support.”*

6.2. Theme 2. Hybrid and continued support

The peer group sessions are flexible, and participant led. The coordinator will ask attendees about individual struggles or experiences since the last meeting, and discussions will then focus on the topics raised. If concerns are unaddressed, they are set aside (“car park”) and followed-up outside of the session, which is an approach that patients greatly appreciate. It helps patients to feel cared for and heard, and removes some of the pressures surrounding independent troubleshooting which can be difficult with brain fog:

> *“And [participating in the group] can also sign signpost you back to the team, if there is something that's important to you that can't be covered [during group session], then the coordinator or someone else from the team will get back to you personally to progress that”*
>
> *“The issue I would say with Living With app and [putting in a request yourself] is given the nature of long COVID you might have had the energy to talk about that for the peer group session, and either fatigue or brain fog might make it completely slip your mind. So, unless there was that follow up process, I think a lot of the opportunity to assist through the peer group might not happen. So, I think it's very good that [SNELCAS staff] do that [reach out with support following group sessions]”*

Knowing that patients are able to voice concerns and queries during sessions, and confidence that they will be handled by a clinician outside of the peer-support group, helps patients to feel cared for by SNELCAS beyond the direct contact time with staff.

6.3. Theme 3. “Pathetic gratitude”: When information and support services are valued but overwhelming

Consistent with themes identified from the patient survey, members of the support group also highlighted feeling somewhat overwhelmed by the volume of referrals and information they received after their referral to SNELCAS. While referrals and resources are appreciated, the sheer volume of options can feel overwhelming and disorienting for some patients with debilitating brain fog and cognitive processing limitations. That being said, a caveat to this theme is that patients feel incredibly grateful and appreciative of the support they are offered. There is an awareness and acknowledgement of there being limited resources in the NHS:

> *“All of the SNELCASS sessions, you know, it’s competing with a lot of other things that we're being asked to devote time to help improve or manage long COVID. So, fitting it in even though it may seem like it's only like an hour of someone's time every other week or so, for example, it can become quite overwhelming just because of everything else that you feel like you're being asked to do.”*

> *“I have that kind of pathetic gratitude really, that I say “yes” to everything because you don't know what's going to stick, you know, and what's going to work for you, but it does mean that then you have to sort of coordinate these different streams of activity.”*

> *“there's a fear of if you say, “well, I can't do it now, I don't have the energy, or I've got three other appointments this during this six-week period. I can't do it”, that it might never come back around again, so there's a bit of a sense of urgency of actually taking the help it when it's offered rather than necessarily when it's best time for you to take it”*

Again, the accessibility of support and offerings to patients was determined not only by the use of technology, but the severity of symptoms that could impede engagement:

> *“It's not so much whether or not you've got technological access, it’s just a side effect of one of your symptoms is a degree of brain fog, confusion, lack of energy, inability to focus. And then you've got a huge amount of information, and you know different potential tools and directions to go,*

> *“Generally organised according to symptoms in the app, and [the difficulty] is how you navigate that and how you prioritise that, given that you're already in a sort of depleted state”*

6.4. Theme 4. Peer guidance and efficiency in information sharing

Participants of the group value it as a hub for learning about additional resources (e.g., KiActiv, ENO Breathe), which they are not consistently aware of or how they might enrol, and for practical problem-solving. For example, referrals to helpful programs often arise through group discussions, particularly for services offered or suggested by SNELCAS. However, one patient also highlighted that patients often conduct their own research, and particularly if individuals are based in the same location, they can sign post each other to helpful opportunities and/or information, that SNELCAS staff may perhaps not be aware of. This is efficient for both patients and SNELCAS staff.

The group helps participants navigate energy trade-offs between accessing support and managing long COVID symptoms e.g., by discussions what activities and services have worked well for them and what happens at participation. The exchange of coping strategies, tools, and advice, which help patients manage day-to-day challenges more effectively without "*reinventing the wheel*” helps patients by saving the time and energy required to undertake their own research, search available resources, and find out how to enrol- instead this information can be shared.

6.5. Theme 5. The Living With app is informative and helpful, but not human

Regarding the feeling of support that patients know they will receive outside of the peer support group, both agreed that "*if [support for concerns voiced during sessions] was left to the app that [patient] would have that same feeling at all*". Information and signposting to resources are appreciated by patients, but it appears that the human element of one-to-one contact with a clinician, particularly one that understands the lived experience of long COVID, is paramount to patient care and cannot be replaced or replicated by anything else. There is also a degree of guidance when discussing an issue with another person compared to searching for solutions independently via, for example, a mobile phone application or digital resource:

> *"There is definitely something about that, you know, human face and human interaction, and especially the given that you know that person has or is still experiencing it themselves"*
>
> *"We're prioritising [energy expenditure], you've got quite often multiple symptoms, some may or may not relate to previous conditions as well, or be exacerbated by the long COVID […] and when you look at the app, you know there are lots of things there- of course that's a good thing, but where to start? And yet, when you're in a conversation with someone, it's somehow easier to identify what it is that is affecting you most at present, or indeed, what impact on your life it is that is causing you the concern at the moment"*
>
> *"therefore I need to think or talk it through with people through that lens, as opposed to the symptom by symptom lens and in the Living with App"*

6.6. Summary

Our dyadic interview with two members of the peer support group showed 5 key themes that are important to patients: patients value the group for its validation and understanding, driven by the leader's lived experience with long COVID, which fosters trust and empathy. This shared space reduces isolation and self-doubt, particularly by addressing the broader life impacts of symptoms. The flexible, participant-led structure allows discussions to focus on individual needs, with unaddressed concerns followed up later, ensuring continuity of care. However, the overwhelming volume of resources and referrals, coupled with cognitive challenges like brain fog, can make navigating support difficult. Despite this, patients express deep gratitude for the support offered, though they often feel pressured to accept it immediately due to fear of losing the opportunity. The group is also highly valued for its practical guidance, allowing members to share resources, coping strategies, and advice, which reduces the need for independent research. Finally, while the Living With app is informative, it lacks the human touch, and patients emphasise the irreplaceable value of personal, empathetic interactions in navigating long COVID challenges.

7. External service suppliers: Onward referrals to external services funded by SNELCAS

Through SNELCAS patients can be referred onwards to external service suppliers, to receive specialised support from citizens advice, mental health, creative health and exercise programmes.

Subsections below include a summary of the services provided, include how each offer bespoke support for individuals recovering from long COVID.

For each of the x services, we conducted one-to-one interviews with service representatives to establish (1) what support was offered to those with long COVID, (2) the specific approach taken, and (3) what, if any, additional support is required to ensure that an adequate service can be maintained to meet the needs of those with long COVID.

7.1. Suffolk Mind

Suffolk Mind is an independent mental health charity in Suffolk that offers in-person and online support and services. Suffolk Mind offer a combination of two offerings for SNELCAS patients: (1) one-to-one 50-minute cognitive behavioural therapy (CBT) focused interventions, and (2) a four-session course consisting of 90-minute sessions, helping individuals to identify their emotional needs and how these have been altered by long COVID.

Approach to supporting those with long COVID

Suffolk Mind offers a **dual-intervention programme** tailored specifically for SNELCAS patients dealing with long COVID. The programme integrates mental health support and adaptive coping strategies to help individuals manage both the psychological and physical impacts of the condition.

The two primary interventions are:

1. **One-to-One CBT Sessions:** Up to 13 individual 50-minute sessions with a trained counsellor, delivered either face-to-face or via telephone.

2. **Adaptive Coping Strategies Course:** A series of four 90-minute sessions designed to help patients recognise and meet their new emotional needs post-COVID. Topics include sleep hygiene, diet, managing low mood, and stress reduction techniques.

The programme is grounded in the understanding that long COVID not only affects physical health but also disrupts emotional well-being. It emphasises the relationship between long COVID symptoms, mental health, and restorative sleep, recognising that improving mental health and sleep quality can contribute to physical recovery.

Patient journey

Patients self-refer to Suffolk Mind via their website, often after suggestion and/or support from a SNELCAS clinician. For patients opting for CBT, there is typically a waiting period of up to four weeks before the first session, followed by weekly meetings with a counsellor. After six weeks, patients complete the CORE-10 survey to evaluate improvements in mental health and wellbeing.

For those enrolling in the coping strategies course, a phone call provides instructions on joining the weekly online sessions, which run over four consecutive weeks. Some patients face challenges accessing the online sessions via mobile devices, and the course has been adjusted to better address the emotional impact of losing previous abilities.

Figure 13 shows that Suffolk Mind was one of the most commonly used external services by SNELCAS patients (almost one third of surveyed patients). We did not survey patients directly about their experience of Suffolk Mind.

What works well about the service offered to SNELCAS patients and is any further support required?

As of June 2024, Suffolk Mind had received over 100 referrals from SNELCAS. Suffolk Mind use a successful, holistic approach that looks at negative thinking and how it arises from unmet needs, the impact on sleep and stress, and sleep on physical symptoms, and physical symptoms that prevent individuals from getting needs met. This approach works well. The charity also has highly trained, skilled staff who are on the team, a rigorous recruitment process and resources for internal and external operation for psychotherapy and CBT. There is also a constant awareness of a need to respond to needs of users as they arise e.g., the changes that people go through as a result of long COVID. The charity did not report any required additional support.

7.2. Citizens Advice Bureau

Ipswich, West Suffolk, and Colchester Citizens Advice Bureaus are independent limited companies, each governed by their own board of trustees. They offer a hierarchy system of advice, beginning with benefits and tax credits, employment, health and community care, followed by support for clients require charitable support (food banks), utilities and communications, housing travel and transport, then education and tax affairs.

Approach to supporting those with long COVID

An in-house social prescriber, funded by ESNEFT, is available to guide patients toward a dedicated long COVID advisor integrated within Citizens Advice. Initially social prescribers were employed 0.5 FTE at each location, with an additional 0.5 FTE in the first year. Dedicated advisors offer direct, hands-on support tailored to the needs of individuals suffering from long COVID, particularly those dealing with physical exhaustion or cognitive challenges that mean their capabilities are limited. The advisor is trained to meet Advice Quality Standards, ensuring high-quality assistance. Patients are often referred internally to specialised teams within Citizens Advice, including welfare benefits specialists who assist with appeals and tribunals, as well as money and debt advisors who provide accredited, formal guidance for managing complex financial issues. This coordinated approach ensures that patients experience a smooth and stress-free journey, even when receiving support in multiple areas simultaneously. The most common internal referrals are related to benefits and tax credits, employment, and access to food banks. Throughout the process, the long COVID advisor remains the primary contact, maintaining consistent communication with the patient until all support needs are fully addressed.

Patient journey

The route for referral is structured, and patient communication is maintained by the dedicated Long Covid adviser, who acts as a central 'point of contact' until all support work is conclude. After Citizens Advice receive the referral, they work one-to-one with the individual to explore issues and needs, research viable options e.g., why they might be having issues with benefits, discuss options with patient e.g., to leave household, remain in household with specific support, and support throughout the decision process especially if additional support is required. Onward referrals can be made internally to other Citizens Advice Ipswich specialist teams – for example the welfare benefit teams (to support appeals and tribunals) or money and debt advisers (where multiple, complex debt situations require accredited and formal debt advice to facilitate solutions for the patient). Through this model, the 'patient journey' can be managed seamlessly and without undue frustration to the patient, even whilst advice is ongoing across multiple areas.

What works well about the service offered to SNELCAS patients and is any further support required?

As of June 2024, between the three Citizens Advice locations, over 355 referrals were made on behalf of or by SNELCAS patients. The service has worked closely with SNELCAS in the design of their offering so that it is bespoke to the needs of patients living with long COVID. It goes beyond signposting, to offer individual case work.

Case studies conducted by Citizens Advice have proven highly effective in supporting individuals with long COVID. The dedicated long COVID advisor is a key feature of this service as it enables the specialised knowledge of financial relief and emotional support most often needed by those with long COVID. Case studies showed that patients regularly receive guidance on employment rights, assistance with applications for benefits such as Employment Support Allowance (ESA) and Personal Independence Payment (PIP), and support with appeals and tribunals.

For instance, one patient avoided resignation, secured PIP and ESA, and received over £2,000 in back payments, alleviating financial stress. Another patient, initially unaware of benefit eligibility, received ESA, PIP, and a Blue Badge, totalling over £13,000 annually, allowing them to retain their home. In another case, a 75-year-old patient, struggling with delayed housing benefits, was awarded high-rate Attendance Allowance and back payments, significantly improving their quality of life. The consistent, personalised support from the long COVID adviser has not only addressed financial and legal challenges but also reduced the emotional burden on patients. However, this bespoke support relies on funding allocated by SNELCAS. As awareness and demand increases, so too does the resulting strain for funding, which is crucial in order to protect and maintain service delivery.

7.3. Cohere Arts

Approach to supporting those with long COVID

Cohere Arts offers creative health activities as a holistic and complementary part of traditional medical services. The programme focuses on addressing specific symptoms like respiratory and cognitive difficulties through activities such as visual art, singing, creative writing, seated yoga, and gentle movement. These sessions target physical health but also foster social interaction and peer support, to support mental health, mood, and sense of connection. Launched as a 12-week pilot of online workshops, the programme's success led to it being re-commissioned for two additional years. Over this period, Cohere Arts delivered 101 workshops and 75 one-on-one creative health consultations, offering personalised support to help patients explore how creative engagement could aid their recovery. Activities were continually adapted based on patient feedback to meet evolving needs.

Cohere Arts also provided creative health training to clinical teams and specialized sessions for artists on addressing cognitive challenges like brain fog. A co-production event involving patients, clinicians, and artists helped review and refine the programme. The key outcome has been empowering participants to adapt to life with long COVID, using creative tools to support their recovery.

Patient journey

In the first year, patients were referred to Cohere Arts exclusively via the SNELCAS clinic. After completing a registration form, Cohere Arts contacts patients to share available activities and arrange a one-to-one creative health consultation. This personalised session helps patients understand how activities like singing (with breathing exercises), visual art, and seated yoga can support their recovery. A follow-up call from the programme manager ensures the programme is tailored to individual needs. The structure of the programme has changed over time, but typically patients will choose from weekly or monthly online and in-person workshops, engaging at a pace that suits their recovery journey.

What works well about the service offered to SNELCAS patients and is any further support required?

The Cohere Arts Creative Space programme has proven highly effective in aiding the recovery of long COVID patients by delivering significant improvements in physical health, wellbeing, and overall quality of life. The programme offered a diverse range of creative activities—including visual arts, singing, creative writing, and seated yoga—through 101 workshops and 75 one-on-one consultations over a two-year period. Participants reported noticeable physical benefits, such as improved breathing, mobility, reduced stiffness, and better sleep patterns. Mentally, many experienced enhanced mood, increased confidence, reduced anxiety, and a greater sense of social connection, with tailored activities effectively addressing cognitive challenges like brain fog. Beyond individual health improvements, the programme fostered a strong sense of community among participants. Patients formed supportive peer networks which helped combat feelings of isolation and provided ongoing emotional support. Many described the workshops as transformative, offering valuable coping mechanisms and helping them accept their new health realities. The programme's adaptability played a key role in its success, with both online and in-person sessions catering to the evolving needs of participants. Engagement levels increased significantly following external advertising and targeted training for clinical teams, which positioned creative activities as a legitimate part of the recovery process. Feedback also highlighted that participation not only provided immediate therapeutic benefits but also encouraged continued involvement in arts and cultural activities, supporting long-term well-being.

The use of specialist arts-health practitioners ensures a patient-focused approach, with activities tailored to individual needs. Co-production between clinicians and artists has been key, blending clinical and creative expertise for best practices, and while getting activities started can be slow, their impact is strong once underway. To improve, more consistent funding is needed to ease patient anxiety about the programme's future. Better marketing and training events for healthcare professionals would also help promote the service and increase referrals.

7.4. Oyster Community Press

Approach to supporting those with long covid

Oyster Press deliver the Road To Recovery programme, specifically developed for those with long COVID. The programme uses the art form of print making to help alleviate specific symptoms identified by SNELCAS clinicians such as brain fog, fatigue, depression, anxiety, confidence, mobility, stiffness and headaches. The activities require engagement with cognitive and motor control, and in doing so supports those with brain dog. Problem solving is less demanding, and the use of hands and tools can be quite intensive, and adaptive techniques allow participants to take their own approach in terms of time.

Patient journey

Patient referrals take place solely through SNELCAS or Community Connectors at ESNEFT. The programme spans across 6 consecutive weeks, with one half-day print making session per week. There are typically 3-6 patients were session, allowing one-to-one and peer support in a calm environment. At end of 6-week period, if patients indicated that they wish to continue this can be arranged as a "bolt on" for another 3 sessions with good uptake.

What works well about the service offered to SNELCAS patients, and is any further support required?

Based on their own evaluation data from 2022-2024, the Road to Recovery printmaking course showed significant positive outcomes for long COVID patients. Generalised Anxiety Disorder (GAD) scores taken before and after the course showed a notable improvement following engagement. Of the 12 patients referred, 11 completed the programme and 10 showed marked improvement in anxiety levels, where one patient improved from 14 to 0, another from 19 to 7, and another from 16 to 5. Only one patient showed a slight increase in anxiety, which was attributed to external circumstances.

To ensure the long-term sustainability of the Road to Recovery programme, several key funding and logistical challenges need addressing. The programme requires stable, timely funding that accounts for both direct delivery costs and essential accommodations for participants, such as transportation support. The current funding model doesn't adequately cover additional sessions or support services that prove beneficial to participants' recovery. Geographic accessibility presents a significant challenge, with some participants traveling long distances, which can be counterproductive to their recovery. A sustainable solution would require either expanded funding to establish multiple delivery locations or resources for comprehensive transportation support, along with budget flexibility to accommodate these necessary program adjustments while maintaining program quality.

7.5. Self-Centre

Approach to supporting those with long COVID

The Self-Centre uses breathing practice and relaxation techniques to address symptoms of long COVID. Activities are all standing, taking a lying and seated focus on the body. Gentle movements facilitate comfortable engagement with the joints and encourage the lymphatic system to work. Deeper, core strengthening work is also sometimes offered. Breathing techniques and meditation based on the senses facilitate the soothing of the nervous system. Patients are supported to manage their symptoms physically and psychologically, and opportunities to engage with social and peer support are available at the end of each session.

Patient journey

Patients are referred to The Self-Centre through SNELCAS and can participate in the course twice; many return to complete the second block. The course itself is a 6-week yoga course. Each week is themed, and sessions last for 1-hour, for a maximum group size of 12. The service has been full for a year with a waiting list but is now receiving fewer referrals from SNELCAS than at the start of service delivery. The adaptability of the programme means that some patients do not consistently participate, however this is compounded by the geographically located offerings.

What works well about the service offered to SNELCAS patients and is there any further support required?

The Self-Centre has highlighted that fewer referrals are being received from SNELCAS at the present time compared to at the start of the service rollout. There is uncertainty regarding the route to referrals and whether patients are aware of the Self-Centre and how they might enrol. There is also an issue of geography, where offers at Woodbridge, Ipswich and Colchester locations have been suggested as a way to diversify the offering, particularly given that many participants can be unable to travel.

7.6. KiActiv

Approach to supporting those with long COVID

KiActiv adopts a technology enabled guided service focused on helping patients to optimise their energy distribution throughout their day, ultimately improving health and wellbeing. Fatigue management and pacing are a key focus, as well as rehabilitation of physical activity and muscle weakness. The goal of the programme to is rehabilitate physical activity and wellbeing to a level that enables patients to undertake a phased return to work and enjoyment of activities to the same level as before they were unwell.

SNELCAS patients receive a wearable device that measures physical activity and intensity of movement. This data is analysed with a patented method and then transferred to a dashboard where the user can gain insights into where their energy is going. The aim is to empower patients to better understand how their energy is distributed, on what activities, at what points during the day, so that they might adapt their self-management strategies.

Patient journey

Patients are signposted to KiActiv through SNELCAS, where the first point of contact is made by the patient themselves. Patients first sign up to KiActiv via the website and arrange an enrolment call and first session with a mentor. This includes 6 telephone sessions across a 12-week programme, the setup of the wearable device and link to mobile phone. The final session takes place at 12-weeks, where around 80% of individuals continue to self-manage following their completion of the programme.

What works well about the service offered to SNELCAS patients and is there any further support required?

Evaluations undertaken by KiActiv have shown good improvements in quality of life, wellbeing and fatigue management. Physical activity data shows people able to do more activities, exercise and general movement is good for fatigue, suggesting it is personalised to their own capacity and constraints. In particular, KiActiv report that their key outcomes improved physical activity levels (78%), mental wellbeing (55%), self-efficacy to manage fatigue (59%), and overall quality of life (81%). Statistically significant gains were observed in home management, social leisure, and private leisure activities. Additionally, 84% of participants completed the programme, with 81% continuing to engage beyond the initial 12 weeks. The programme also showed a strong return on investment of £9 for every £1 spent. KiActiv argue that the offering works effectively when it is embedded within a pathway, and did not offer any suggestions or notable requirements for improvement.

7.7. Sport for Confidence

Approach to supporting those with long COVID

Sport For Confidence takes a holistic, person-centred approach to supporting those with long COVID through a combination of educational sessions and physical activity. Their 6-week educational program helps participants understand and manage symptoms like fatigue, and weekly transition groups provide gentle physical activity and social support. The program is delivered by occupational therapists who create individualised interventions based on each person's capabilities, needs and goals, to help participants return to meaningful activities. The model emphasises peer support and community, and idiosyncratic patient support.

Patient journey

Patients are referred to Sport for Confidence through ESNEFT and typically wait up to 8 weeks for initial assessment. The core program consists of two weekly sessions over 6 weeks: an educational session covering topics like fatigue management, and a transition group focusing on gentle physical activities. Each session lasts approximately one hour. After completing the 6-week program, participants can join an optional 4-week follow-up program and many attend transition groups for ongoing support. One to one interventions are also offered to participants, ranging between 1-4 sessions.

What works well about the service offered to SNELCAS patients and is there any further support required?

The recent evaluation report by Sport for Confidence demonstrates good effectiveness in supporting those with long COVID. Improvements in anxiety levels, fatigue management, and overall wellbeing were all evidenced. Participants report enhanced ability to engage in daily activities, work, and social interactions. The program's success is particularly evident in the transition from initial high GAD scores to lower scores post-intervention.

However, to ensure programme longevity, several key supports are needed: consistent and timely funding that accounts for both direct delivery costs and essential accommodations like transportation, expanded geographic accessibility to reduce travel barriers, and budget flexibility to accommodate necessary program adjustments. The current funding model needs enhancement to cover additional beneficial sessions and support services that are currently unfunded but prove valuable to patient recovery.

Summary

External services commissioned by SNELCAS address various needs of patients with long COVID, including mental health, creative recovery, physical rehabilitation, and financial guidance, offering tailored interventions to improve patients' quality of life and well-being. The services described good efficacy in supporting patients’ long COVID recovery, offering tailored interventions that address physical, mental, and emotional needs. Programs like Suffolk Mind and KiActiv show measurable improvements in mental well-being, physical activity, and fatigue management. Creative health services such as Cohere Arts and Oyster Community Press enhance mood, cognitive function, and social connection, while Citizens Advice helps alleviate financial stress with practical support. However, despite their successes in the majority of cases, improvements are needed in consistent funding, better geographic accessibility, and expanded service delivery. Addressing these issues would enhance long-term sustainability and ensure more equitable access for patients.

Process mapping

Figure 14, below, illustrates the typical SNELCAS patient journey as of April 2025.

Referrals are received electronically by the SNELCAS Care Coordination Centre, and automatically added to a clinical waiting list hosted on System One, for their initial one-to-one assessment. SNELCAS administrative staff organise then initial assessment appointment with the patient via their preferred contact method. In the meantime, patients are send an invitation to begin using the Living With mobile application, and filmed content for self-management support.

At their **initial one-to-one assessment**, with the support of clinicians patients complete health questionnaires embedded within System One including common symptom profiles of Long Covid, C19YRS, and their first EQ-5D-5L scores are taken. Specific needs are also addressed e.g., benefits, housing, work, relationships. Here, therapeutic referrals are offered to patients, including Citizens Advice and Social Prescribing, where appropriate. One-to-one assessments are also the first instance of medical safety netting, to establish whether the patient case is one of typical long covid or whether there are other medical needs and/or co-morbidities that are not maximally managed. If so, patient cases will be progressed by SNELCAS clinicians to the next multi-disciplinary team meeting (MDT). Note, patients 16-17 years of age are automatically submitted for discussion at MDT meetings.

Multi-disciplinary team meetings occur virtually, twice per week, and are where the majority of **onward medical referrals** take place. SNELCAS staff can add any patient cases to be discussed at MDT meetings. Standard MDT meetings consist of 2 Care Coordinators, a Senior Occupational Therapist, Clinical Lead, Speech and Language Therapist, Assessment Clinicians, ED Consultant and a Specialist GP. Note that items for discussion at MDT meetings are not solely medical, and other issues can be introduced including the discussion of appropriate therapeutic pathways for patients. Discussions are iterative and patient cases can be introduced and re-introduced to any MDT meeting during any point of their engagement with the SNELCAS service. **Internally organised diagnostics** including bloods, CT scans and X-rays can be organised internally. Referrals to secondary care can also be arranged and further diagnostic testing requested. Findings are discussed at MDT meetings for review and then communicated with both patient via their preferred contact method (e.g., email, telephone, Living With application). Findings are also communicated back to patients' GP tasked through System One, in cases where additional co-morbidities have been identified e.g., pre-diabetes, high cholesterol and/or general health issues; those with no obvious requirement for onward secondary care specialism and are not Long Covid-related.

Following their initial one-to-one assessment and (in some cases) case discussion at MDT meetings, patients are added to the System One waiting list for their **3-monthly follow up assessments**. Three-monthly follow up appointments are conducted by clinicians. After their first 3-month follow up appointment, patients are introduced to the 6 Week Self-Management Programme and any therapeutic onward referrals e.g., those with external service suppliers. Successive 3-monthly referrals are a "stock take" for self-management capability, symptom improvement, suitability of therapeutics and eligibility for new offerings. At this point, the progression of the patient pathway becomes more personalised according to the trajectory of their recovery. Upon completing the 6-week self-management programme, patients are then invited to participate in the Peer Support programme.

This process is iterative and continues until the point of patient discharge.

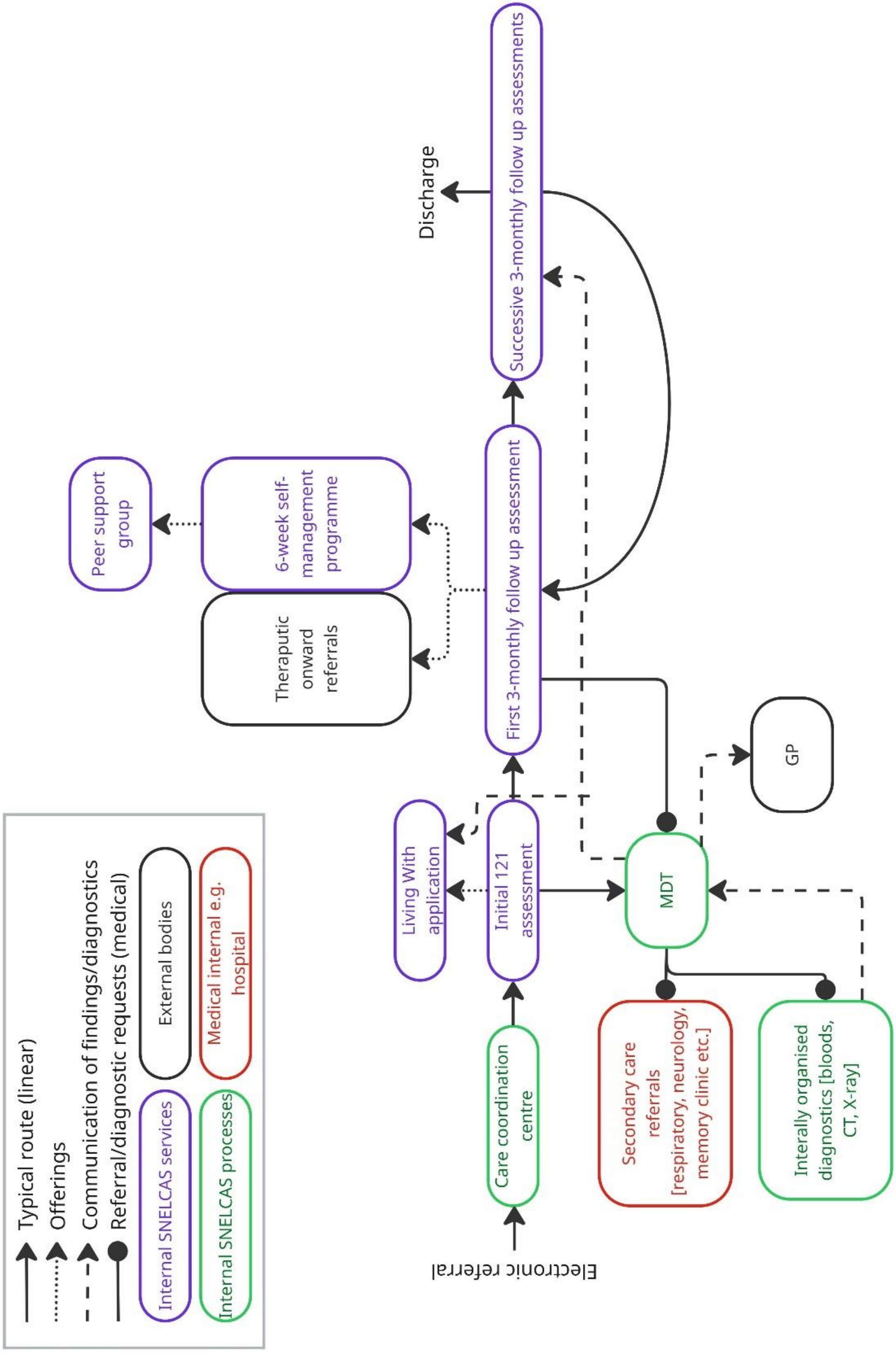

Figure 14. Process map of the patient journey through the SNELCAS service, as of April 2025.

8. Overarching summary

8.1. Overall, is SNELCAS effective in treating long COVID?

Our analysis of **EQ-5D-5L scores** suggests that SNELCAS is effective in improving patients' overall physical health and quality of life. Significant gains in dimensions like Self-care and Usual Activities indicate that patients experience enhanced functionality and independence post-discharge, and although average scores for Mobility, Pain/Discomfort, and Anxiety/Depression did not change in terms of averages, there is a statistically significant shift in scores towards less severe ratings in these dimensions, showing a positive impact for many patients. The 10% increase in self-reported health status (VAS) further reinforces the perception of better health, demonstrating that SNELCAS contributes meaningfully to patients' recovery and well-being.

This finding is reinforced by **patient survey data**. Patients praised the service's emotional and practical support. Emotional validation and empathy from specialists were frequently cited as highlights, as they helped patients feel understood and reassured. Most patients feel well-supported by SNELCAS, though there are areas for improvement (see below). The majority appreciate the clarity and helpfulness of the initial referral process, suggesting that the service is generally effective at providing information about recovery resources and next steps, demonstrating a strong foundation of administrative support. The initial assessment experience is mixed but mostly positive. Patients value face-to-face interactions the most, as these offer a greater sense of connection and thoroughness. However, telephone assessments—while convenient—are often less satisfying, particularly for those who were not given an option to choose their preferred method. Some patients felt rushed or that key information was missing during the assessment, highlighting a need for more attentive care. Patient involvement in decision-making appears adequate, with most feeling engaged in their care planning. Similarly, the vast majority felt treated with respect and dignity, indicating that staff interactions are generally compassionate and professional. However, gaps in communication about next steps and waiting times leave some patients feeling unsupported or uncertain about their treatment journey (see below). The fact that 73% believe SNELCAS positively contributed to their recovery shows that the service has a meaningful impact on many patients' lives. Yet, the remaining patients who were neutral or dissatisfied suggest that improvements in follow-up communication, treatment planning, and reducing delays could significantly enhance the service's support. Coordinated care, including referrals to specialists, therapy, and effective interventions like the ENO breathing course, was valued as a significant improvement over previous experiences of GP-led approaches. Practical tools such as the Living With app and external coping workshops empowered patients to better manage their condition, and personalised care and regular check-ins provided reassurance. The sense of community fostered through group activities and peer support helped reduce isolation, offering both emotional relief and practical advice.

However, patients also identified areas for improvement. Communication issues, including delays, inconsistent updates, and poor follow-ups, left some feeling unsupported and forgotten about. Suggestions to mitigate these included clearer updates, communication between appointments, appointment reminders and more opportunities for peer-support. The impersonal nature of some remote consultations and challenges with poor record-sharing were noted as frustrations, with patients recommending more face-to-face appointments and tailored care plans. Accessibility was another concern, with patients calling for more local and flexible service options, though notably understanding that services are inherently limited. Within the theme of accessibility was the overwhelm that my faced when it came to the communication of information. The majority of patients are appreciative of the information and signposting that they receive, but their symptoms often prevent them from being able to engage in a consistent and timely manner with the content, which can in turn lead to feelings of discouragement, anxiety and helplessness. Finally, while peer support was highly valued, some patients expressed disappointment at not having the opportunity to participate.

8.2. Is SNELCAS a positive working environment for staff?

It should be highlighted here that we only received **survey responses from 6 SNELCAS staff**, and so findings may not necessarily representative of the views of other staff members. Staff feel that SNELCAS performs well in several key areas but also has room for improvement to better support its employees and enhance service delivery. Staff highlighted effective referral processes for diagnostics, subspecialties, and external services, though variability in criteria and system navigation challenges were noted as areas requiring attention. Communication between SNELCAS sites was generally effective, but outreach to GP practices needs improvement to ensure consistent understanding and referrals. While team collaboration works very well according to most, hybrid working practices and disengagement during virtual meetings posed challenges. Administrative support was well-regarded, though additional training on System One could help staff manage multiple record systems more efficiently. Suggestions to centralise forms, update criteria, and improve communication during team meetings were noted as ways to enhance internal consistency. Staff also rate the quality of patient care very highly, though consistently with responses from patients, highlight that not all patients receive equal treatment and service engagement. Inconsistencies in advice regarding onward referrals and service offerings were identified, as well as language barriers and accessibility issues, including upstairs clinics. Discussions and increased face-to-face support in underserved areas were recommended to address these concerns.

Therefore, SNELCAS is generally a very positive working environment for SNELCAS staff, but there are still key areas that require some improvement.

8.3. Efficacy of external services

In terms of the external services offers to patients, patients greatly benefit from accessing external services, with mixed but generally positive feedback highlighting their impact.

According to *patient* feedback, the CAB was particularly valued for financial support, with 80% of respondents finding it useful, though only half reported a significant recovery impact. Notably case studies received from CAB demonstrate in more granular detail the invaluable support offered to patients. Peer support and shared experiences in the six-week self-management group helped patients feel less isolated and validated their symptoms, with 87% finding it useful. However, the virtual format and cognitive demands were challenging for some. KiActiv offered personalised feedback and helped patients manage energy levels, though technical difficulties and cognitive overload were common concerns. Sport for Confidence provided face-to-face peer support and practical advice, though limited availability and session structure affected accessibility. Lastly, the Living With app helped patients track symptoms and access support, but some felt overwhelmed by the information provided. Across services, feedback suggests that personalisation, simplified content, and more flexible delivery methods could enhance patient experience, while peer support, practical tools, and validation remain key benefits. Note that feedback from many patients did somewhat contrast with the reported findings from the evaluations undertaken by external service suppliers. Though not in any concerning way, it is clear that patients are not completely fulfilled and consistently supported with commonly encountered issues with the offerings of service suppliers, specifically with KiActiv, Sport for Confidence, and the Living With mobile phone application to some degree.

8.4. Suggestions for improvement

Serving a diverse population

The SNELCAS patient demographic aligns well with local populations in terms of age distribution, with most patients aged 50–64 years, reflecting Suffolk and Essex's population. The gender split shows more women accessing the service, which aligns with the higher prevalence of long COVID in women. However, there is a notable underrepresentation of patients from Asian, Black, and Mixed ethnic backgrounds, despite these groups being disproportionately affected by long COVID. Actions to improve the accessibility of the service to a more diverse population could include (1) **targeted outreach**, such as community engagement strategies aimed at increasing awareness of the service among underrepresented ethnic groups, (2) **cultural competence trainin**g for staff to improve trust and awareness among non-white British patient populations, (3) **regular data monitoring** to regularly evaluate a breakdown of the patients referred to and attending the service, adjusting outreach efforts accordingly, and (4) **partnerships with local organisations** such as faith groups and BAME communities to enhance the visibility (and trust) of the service.

Indeed, most patients are referred to SNELCAS by their GP (43%) or approach their GP themselves (46%) believing they have long COVID, and most patients (89%) had *not* heard of SNELCAS prior to their referral. Together this highlights challenges for some when it comes to securing a referral, and an absence of awareness of the service within the community.

Adapting the 6-week self-management programme

To improve the 6-week self-management programme, several key strategies could be implemented based on patient feedback. First, tailoring sessions to meet individual needs by **grouping participants based on symptom severity** or specific issues would ensure more targeted and relevant content, reducing unnecessary energy expenditure. Offering smaller group sizes would allow for personalised advice and more opportunities for interaction, while also preventing individual participants from dominating discussions. Second, the **recording of sessions** that are then stored in a local, easy-to-locate archive would enable patients to engage at their own pace and revisit content as needed, particularly for those struggling with cognitive overload or screen fatigue. Increasing the **interactive elements** of the sessions, such as live Q&A opportunities and dedicated peer-support time, would help balance the delivery of information with shared experiences, which patients found highly valuable. Lastly, **simplifying content and reducing the cognitive demands** of virtual delivery—such as limiting technical language and offering shorter, more digestible segments—would make the programme more accessible. While the virtual format has practical benefits, offering a mix of online and face-to-face options could provide flexibility and better accommodate patients with varying needs and comfort levels.

Keeping information overload in mind

Our findings show a recurring theme where it is the symptoms of long COVID that prevent patients from fully engaging with the resources and services that could most support their recovery journey. This includes limitations to process and retain content shared during the 6-week self-management programme, but also navigation of the interface of the Living With application and engagement with external offerings. Patients describe feeling incredibly appreciative of the services, resources and signposting to information that is available to them through SNELCAS but describe both (1) difficulty to organise and utilise this information due to feeling overwhelming, and (2) a feeling of “pathetic gratitude” where they will attend events and/or activities that may not necessarily be relevant or beneficial for them, causing inefficient energy expenditure as a result. Ensuring that information sharing, of any kind, is efficient in that it (1) reaches those it is most relevant to, (2) presented in a clear and orderly manner, (3) grouped by themes and priorities and (4) easy to navigate. Accessible services, in terms of frequency of meetings, one-to-one support, smaller group sizes, and more local opportunities to engage with practical and physical activities are also all suggestions that would help more patients to comfortably and consistently engage.

Maintaining clear, consistent communication with patients

The majority of SNELCAS patients completed their initial assessment 6-10 weeks and discharge typically happens between 31 and 70 weeks. Moreover, feedback from patient surveys showed that communication was a major concern, with many reporting delays, inconsistent updates, and poor follow-ups that left them feeling frustrated and unsupported. To improve communication with patients, SNECLAS could offer more **frequent check-ins and updates**, particularly clinician-led and every 4-6 weeks, so that patients could track when next to expect to receive contact.

Note that under the current pathway model, patients are recurrently seen every 3-months for follow-up assessments and appointments. However, reducing 3-months to, perhaps, 2-months, would help patients to feel more in sync with, and staff more aware of, the progress of referrals, upcoming appointments, and engagement with services. Although a primary function of the Living With application appears to be a pathway to ensure this, some patients are still feeling forgotten. The development of a **centralized patient portal** would facilitate appointment tracking, referrals, and available services. Whether this currently is or could be an integrated feature of the Living With app could be explored. Information on how to access various programmes, including their availability would be useful. Ensure that patients are receiving **appointment reminders and follow ups** that are automatic, easy to read and navigate, and that reminders are sent more than once in the follow up to appointments and scheduled activities. Some patients may also require phone call reminders. **Clear communication of service availability** including outline of the services, eligibility criteria, and self-referral options will also help patients to see their place within the pathway and clarify uncertainties. **Case coordination and advocacy** is crucial for supporting patients and providing personalised care. Assigning a care coordinator to patients will optimise continuity of care, follow ups on outstanding referrals and liaising with other services e.g., GPs or external diagnostic providers to prevent delays in treatment and care. Ultimately, a positive **patient feedback loop** will enable patients to provide feedback on their experience at regular intervals, such that barriers can be addresses and the efficacy and efficiency of treatment can be maximised. A focus on acting on their suggestions will improve the efficacy and efficiency of the service delivery.

More opportunities for peer support

Patients who can access peer support groups often report positive experiences, highlighting the benefits of feeling understood and heard by others with similar experiences of long COVID. However, our broader data, including patient surveys and feedback, indicates that **not all patients are not being offered these opportunities** to connect. This suggests a need to ensure that treatment opportunities are consistently offered to everyone, preventing any group from being left behind. Participants express a need for a **moderated platform** where they can interact between meetings to ask questions or share insights in real-time. While confidentiality concerns are noted, this gap limits the group's continuity and immediacy. Enhancing the Living with App to allow moderated peer interactions or to simplify resource navigation could address current accessibility challenges is an obvious way to address this. The SNELCAS **peer-support group** could be improved in several ways. Increasing the frequency of sessions, such as offering bi-weekly meetings or shorter check-ins, would enhance continuity and engagement. Introducing a moderated platform within the Living With app for inter-session communication could help participants connect safely between meetings, while simplifying the app's navigation and organisation resources by themes or priorities would address the challenges of cognitive fatigue. Offering **hybrid or offline alternatives**, like telephone-based support, would accommodate those with limited access to or tolerance for digital tools. Raising awareness of lesser-known programs through structured "**resource spotlights**" in meetings or newsletters could improve resource utilisation.

Improving the working environment for SNELCAS staff

While communication between SNELCAS sites is generally effective, improving **outreach to GP practices** is essential to ensure consistent understanding of referral processes and criteria. Standardising communication protocols for virtual meetings could reduce disengagement and strengthen hybrid working practices. **Regular in-person team check-ins** could also improve collaboration and communication and ensure that engagement remains prominent in a hybrid approach. Staff would benefit from additional training on **System One** to manage multiple record systems more efficiently, and similarly the centralisation of forms and updating referral criteria would help improve consistency and reduce administrative burden. Finally, some staff raised queries regarding the **equity and accessibility of patient care**. Clearer, more consistent advice on onward referrals and available services is needed. Staff should be equipped to deal with cultural and physical accessibility needs of patients.

Evaluating the progress of external support services

To ensure SNELCAS patients consistently benefit from external services, several strategies can be implemented. First, **introduce regular, independent evaluations** of external services to cross-check supplier reports with patient experiences, ensuring a balanced and unbiased assessment. An internal, SNELCAS-owned "**evaluation toolbox**" would ensure that experiences and outcomes for patients are comparable across time and services. **Patient follow-ups at different stages**—not just immediately after service use—could help capture long-term outcomes and identify persistent issues. Indeed, the suggestion outlined previously of more frequent and consistent communication with patients would provide opportunities to capture any issues when they arise. Ensuring that services are understanding of the needs of long COVID patients from the offset is key. Although this seems to be true in most cases, many patients still require simplified processes that are compatible with their symptoms e.g., for services like KiActiv and the Living With app, **simplifying content and offering in-person onboarding** could reduce cognitive overload and improve usability. Finally, **establishing stronger feedback loops** between patients, SNELCAS, and service providers would ensure continuous improvement and allow adjustments based on real-time concerns. These steps would help SNELCAS maximise the value of its investment into external services, making sure that patients feel consistently supported and cared for. Indeed, a suggestion by SNECLAS staff was the consistency and improved participation in regular MDT meetings. Perhaps a similar, dedicated approach could be taken for external service suppliers.

Funding requirements

As with long-term procurement of funding for enabling patient access to therapeutic intervention hosted by external service suppliers, establishing consistent, long-term funding for the SNELCAS service is crucial to maintain a medical assessment service that provides an effective, specialised service to patients outside that bypass secondary care pathways. Consistent, long-term funding would enable (1) staff recruitment and retention, enabling job security and satisfaction of medical professionals, (2) service continuity and reliability for service users, ensuring reliable and uninterrupted healthcare that is not at risk of gaps in service delivery and does not leave patients without specialised, clinical support, (3) optimal planning and scaling of the service to continue to reduce demand on external medical areas, through strategic investment in long-term service model efficiency and growing demand in wider populations; notably, not only for patients living with Long Covid, but potentially also for similar chronic conditions whose symptom profiles are akin to Long Covid e.g., chronic fatigue, fibromyalgia, (4) a cost efficient assessment service that bypasses gaps in service delivery and staff turnover, and (5) the placement of the SNELCAS service within the both the local community and ESNEFT landscape, in a way that can facilitate trust with patents and clinical stakeholders, and reduce the burden on associated services.

Findings from the present evaluation demonstrate that the SNELCAS service is experienced positively by patients both in terms of perceived support and symptom improvement. The service plays a vital role in patient recover and overall wellbeing and has the potential to do so for those living with similar chronic conditions. Ensuring access to consistent, long-term funding is essential to maintain this impact, and to maximise the broader impact and scalability of the SNELCAS service.