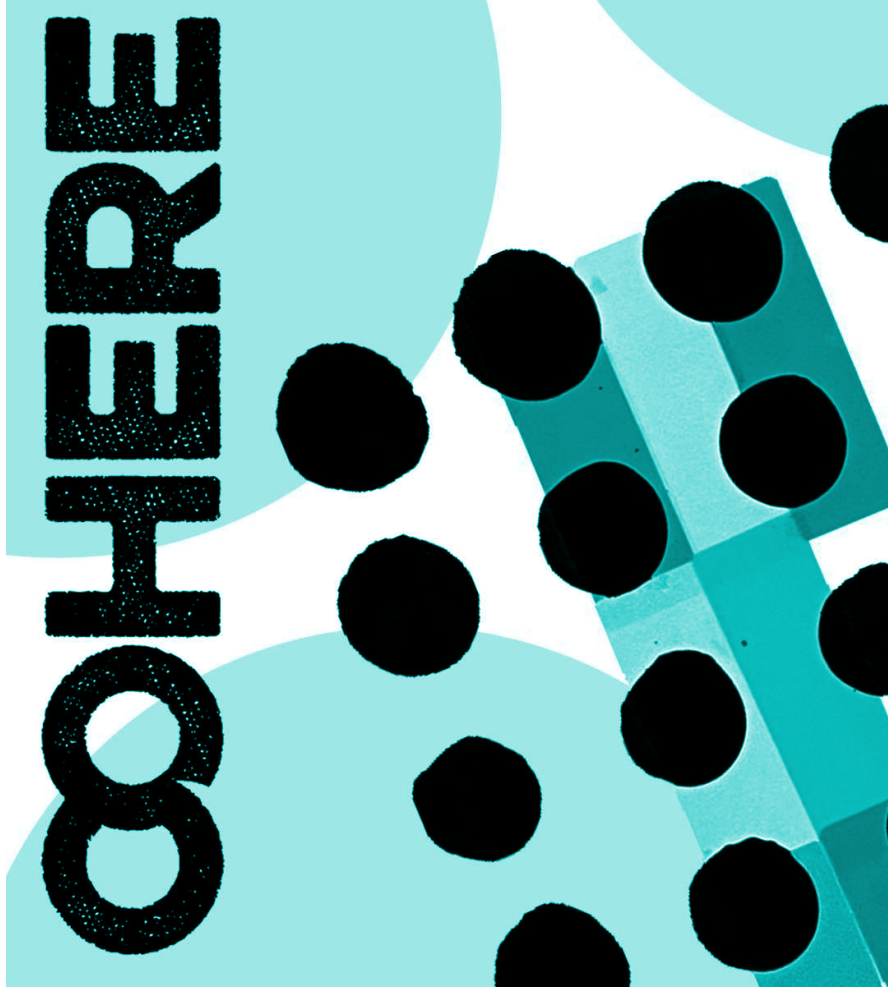


Creative Space



**A 2-year creative health programme to support
the recovery of people living with long covid**

**Programme Evaluation
March 2024**

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Executive Summary

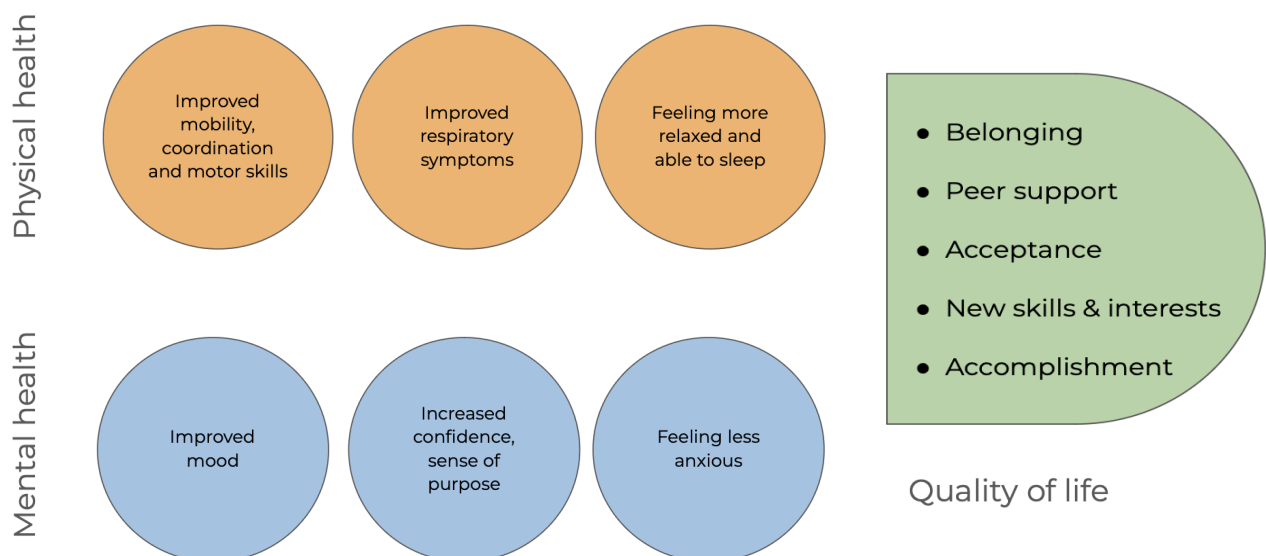
In January 2022, Suffolk and North East Essex Long COVID-19 Assessment Service (SNELCAS) commissioned Cohere Arts CIC to develop *Creative Space*; a programme of online creative workshops for patients living with long covid. After a 12 week pilot, a 2 year programme of activity was delivered between April 2022 and March 2024.

RECRUITMENT, DELIVERY & ENGAGEMENT

- 165 patients were referred or self referred to the programme
- 101 workshops were delivered by specialist arts-health practitioners in visual art, singing, creative writing, seated yoga, gentle movement (95 online, 6 in person)
- 75 1 to 1 creative health consultations were delivered via telephone
- 35 online video resources were published
- 1 co-production event was held (one as part of a National Centre for Creative Health initiative)
- 1 creative health training session was delivered to members of the clinical team
- 1 training session on brain fog was delivered to Cohere artists
- A co-productive, cross-sector approach to programme development was adopted, with the programme continually adapted in accordance with participant need
- Engagement improved after external advertising and self-referrals were introduced and even more dramatically after a creative health training session was delivered to clinical team members

IMPACT

Analysis of evaluation data collected at regular intervals throughout the programme indicates that taking part in Creative Space activities had a range of positive impacts on the physical/mental health and general quality of life of patients living with long covid, most notably in the following areas:



LEARNING

- Regular engagement in creative activities can be effective in supporting recovery from long covid
- Buy-in from clinical teams has been essential for recruitment and engagement
- Creative activities can be tailored to stimulate cognitive function
- Specific arts-health expertise and an inclusive ethos is key
- More medicalised language in communication and promotion of the programme is effective
- Meeting evolving patient needs requires a reflexive and co-productive approach to programme design
- Work is needed to attract more male-identifying participants
- A positive experience of a creative health programme can encourage further participation in arts and cultural activities and the use of creativity as a wellbeing tool

Background

Cohere Arts CIC

Based in East Suffolk, Cohere Arts is a community interest company creating opportunities for people (especially those living with long term health conditions & disabilities) to improve their health & wellbeing through engagement with arts & culture through:

- performance projects
- a programme of regular creative health activities
- sharing our learning through training & advocacy.

Their projects include working with adults living with visual impairment, Parkinson's, long covid & other health/mobility issues, and young people with mental health challenges.

Suffolk and North East Essex Long COVID-19 Assessment Service (SNELCAS)

Long Covid is defined by the National Institute for Health and Care Excellence (NICE) as:

'Signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis'.

Patients living in Suffolk and NE Essex who have been experiencing coronavirus symptoms for more than 12 weeks can be referred by their GP to the Suffolk and North East Essex Long COVID-19 Assessment Service (SNELCAS), a virtual clinic that gives patients access to appropriate services or specialist clinics for their needs.

Long covid is a multi-systemic, long-term health condition, requiring a multi-pronged and multidisciplinary approach to treatment. NICE guidelines recommend the inclusion of occupational therapy, physiotherapy, clinical psychology, psychiatry, and rehabilitation expertise within multidisciplinary teams around the patient. In the SNELCAS team, social prescribers are amongst the many healthcare practitioners working collaboratively to provide holistic support to patients.

In Nov 2021, there were an estimated 14,500 people living with long covid in Suffolk, with 878 referrals made to SNELCAS. By Feb 2023 the number of patients referred to SNELCAS had risen to 2154.



Creative arts for long covid rehabilitation

There is a large body of clinical and academic evidence to support the notion that engaging in arts and cultural activities can enhance our physical and mental health and wellbeing^{1 2} and also address health inequalities³. Engaging in activities such as singing, dancing, drama and visual arts has been shown to have specific physical benefits (e.g. pulmonary/cardiovascular function, dopamine stimulation, speech regulation, improved balance, coordination and cognition). Joining with others to take part in these activities can address isolation and improve mood, and the mindful act of making and creating can instil a sense of relaxation, improved self-esteem and accomplishment.

For people living with long term and more complex health challenges like long covid, recovery time can vary widely, from weeks to months. Engaging with creative activity during this time can offer many positive health and wellbeing impacts, ranging from distraction and relaxation to skill development, increased confidence and feelings of accomplishment. Group activities can offer connection and peer support as an antidote to the isolation that ill-health can bring. Delivery can also be designed to address specific symptoms; for example breathing exercises for respiratory issues and anxiety, hand-eye coordination tasks to stimulate cognitive function and movement for cardio and physio rehabilitation.

Clinical evidence supporting the use of arts interventions in the management of long covid is currently limited due to the very recent emergence of the condition. However, the first randomised control trial (RCT) surrounding the efficacy of online singing and breathing by Philip et al (2022) suggests that English National Opera's BREATHE programme has had a positive impact on the breathlessness and mental health symptoms of trial participants⁴. This pioneering study highlights the urgent need for additional research in this area whilst reinforcing current guidance around the management of long covid; in particular the need for holistic, multidisciplinary approaches that address the nuances of the condition and the needs of the individual.

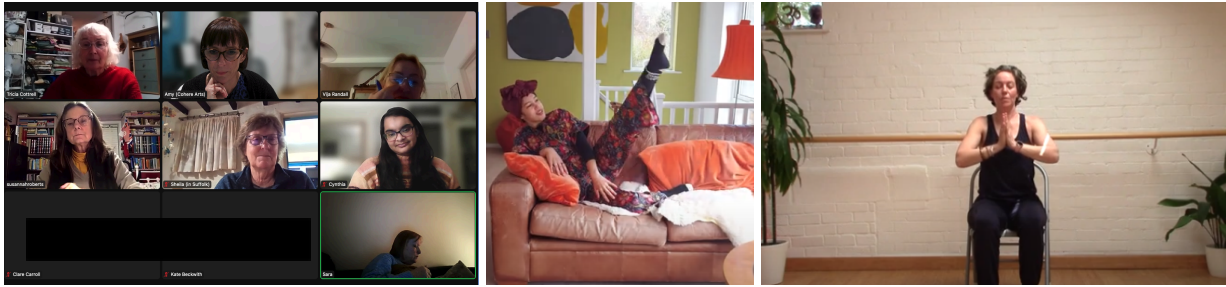
¹ Fancourt, Warran & Aughterson (2020) *Evidence Summary for Policy: The role of arts in improving health & wellbeing*, report for the DCMS

² Fancourt & Finn (2019) *What is the evidence on the role of the arts in improving health and well-being? A scoping review*

³ Mak et al (2020) *Does arts and cultural engagement vary geographically? Evidence from the UK household longitudinal study*

⁴ Philips et al (2022) 'An online breathing and wellbeing programme (ENO Breathe) for people with persistent symptoms following COVID-19: a parallel-group, single-blind, randomised controlled trial'

Lancet Respiratory Medicine



Creative Space programme

In January 2022, Suffolk based organisation Cohere Arts were commissioned by East Suffolk and North East Essex NHS Foundation Trust to provide creative health interventions for patients of their long covid assessment service. The aim of the Creative Space programme was to enable patients to access the potential benefits of engaging with creative activity alongside more clinical routes. The programme was designed to offer a range of activities so that participants could choose how and when they engage, and are encouraged to take part in a way that suits their energy levels and how they are feeling that day.

A 12-week pilot programme was developed in partnership with the clinic, beginning as a series of free online workshops in creative writing, visual art, gentle movement and singing, each led by specialist arts-health practitioners. One hour sessions combined practical exercises with social time, meaning participants could learn new skills whilst connecting with other participants facing similar challenges. At the end of the pilot period, participants recorded slight reductions in perceived levels of the measured symptoms; fatigue, brain fog, poor memory, social isolation and anxiety, with social isolation most significantly improved. Those who had engaged most frequently saw the most positive impact.

Following the pilot, the Creative Space programme was extended for two more financial years (2022-2023 and 2023-2024). A co-productive, patient-centred approach ensured the programme was continually redeveloped in response to the changing needs of patients. For example, at one point many were having to return to work despite facing continuing health challenges, therefore online content was created that could be accessed at any time. In latter months, a need was expressed for in-person events, so workshops were held in cultural spaces with the support of arts organisations Mercury Theatre and Ipswich Museums. A good dialogue was established and maintained between SNELCAS, Cohere Arts and patients, enabling agile and flexible ways of working that facilitated cross-sector learning.



Recruitment, Delivery & Engagement

	Recruitment	Programme	Engagement
PILOT Jan 2022 - Mar 2022	30 patients referred by SNELCAS	1 to 1 creative health consultations 24 online workshops (singing, gentle movement, creative writing and art)	1-5 participants per workshop, most popular sessions singing and art
YEAR 1 Apr 2022 - Mar 2023	37 additional patients referred by SNELCAS	1 to 1 creative health consultations 34 online workshops (singing, gentle movement, creative writing and art) 25 online resources (YouTube videos) Promotional video with participant testimonials	21 regular workshop participants, attendance gradually lessening Most viewed video had 363 views Many participants reporting having to return to work or having conflicting priorities
YEAR 2 Apr 2023 - Mar 2024	98 additional patients via SNELCAS or self-referral Social media used to promote self-referrals Increased clinic referrals following training	1 to 1 creative health consultations 17 online workshops (singing, creative writing and art) 26 online seated yoga classes 6 in-person Art Cafes 10 seated yoga videos published Training & co-production events for artists/clinical team Greater focus on brain fog	52 regular participants of online activities, group sizes averaging 10-15 per session 10-15 regular attenders of in-person activities Need expressed for in-person events Participants accessing other Cohere Arts activities in addition to this programme
OVERALL Jan 2022 - Mar 2024	165 registrations to the programme (with 10 subsequent withdrawals)	75 1 to 1 creative health consultations delivered (via telephone) 101 workshops delivered (95 online, 6 in person) 35 online video resources published (art, singing, creative writing, dance, seated yoga) 1 co-production event with patients, artists, social prescribers and clinical team members 1 training session in brain fog delivered to artists 1 training session delivered to clinical team	A well-established core group of regular participants accessing a range of activities as well as Cohere Arts wider creative health programme Emerging communities of outside of our programmes within patients (e.g. a WhatsApp group with 20 members) Growing acceptance of creative health activities as a legitimate route to health & wellbeing

Recruitment

Initially, referrals were coming solely from the SNELCAS team and group numbers remained limited. In year 2, Cohere Arts advertised the programme outside of the SNELCAS patient group and saw an increase in numbers due to self-referring patients.

Co-production events and training sessions were instrumental in raising awareness of the effectiveness of the programme, and in particular, Cohere Arts saw a huge increase in both referrals and self-referrals from Jan 2024 onwards.

Recruitment was supported by promotional material including a promotional video featuring testimonials of participants. Co-production work with health colleagues instigated a move towards using more medicalised language in promotional material which encouraged patients to see the programme as a legitimate aspect of their treatment.

Delivery & Engagement

1 to 1 consultations were offered to every patient who registered with the programme. These proved highly effective as a method of 'onboarding', and building confidence in patients to try activities and resources. Activities offered began with weekly online workshops in singing, gentle movement, creative writing and visual art. As patients began to return to work, engagement lessened, so a range of online resources were created. Seated yoga was introduced instead of gentle movement, proving a popular and effective option.

As people living with long covid regained confidence in getting out and about, our participants expressed a need for in-person events (and more creative writing workshops) which were added to the programme. Noticing workshop attendees were mentioning particular benefits around neurological symptoms, artists attended training led by clinical colleagues around brain-fog, enabling more focused tailoring of creative activities to address these symptoms.

“I went to a creative writing workshop through Cohere Arts and it was really fun, a nice group of people and all online. Also a nice way to try and stretch my brain but with a group of people who completely understand you lose the plot (of the story!) or forget what's been said. It was actually memory training in the way the session was structured as well as fun.” - participant

Perhaps most significantly, over time Cohere Arts saw communities of peer support develop amongst participants. Regular attendees also began to access other workshops and events run by Cohere Arts, and continue with creative activities independently, at home and with family members/carers.

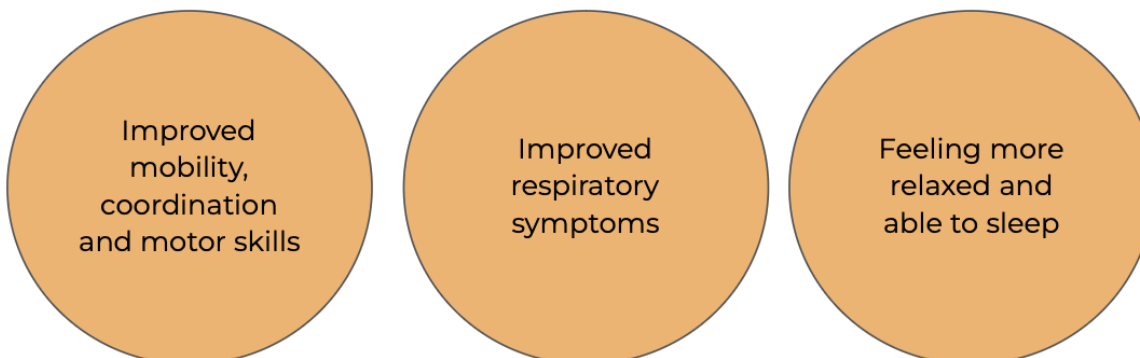
Impact

Following a more structured evaluation of the 12 week pilot, evaluation activities throughout the programme have included regular e-surveys, post-workshop feedback captured via e-survey and email, group discussions and more in depth interviews. Evidence is largely qualitative. Engagement in evaluation activities has varied, however definite themes around areas of impact have emerged.

	Evaluation activities	Impact
PILOT Jan - Mar 2022	<p>Jan 2022 - Baseline survey measuring patient perception of 5 symptoms; Fatigue; Brain fog; Poor memory; Social isolation; Anxiety - 16 responses</p> <p>Post-workshop feedback forms - 30 responses</p> <p>Mar 2022 - Post pilot review - 8 responses</p>	<p>Workshop feedback highlighted positive impacts of singing/learning breathing exercises</p> <p>Patients recorded slight reductions in perceived levels of 5 symptoms: Fatigue; Brain fog; Poor memory; Social isolation; Anxiety</p> <p>Social isolation most significantly improved</p>
YEAR 1 April 2022 - Mar 2023	<p>Sept 2022 - Survey capturing perceived symptoms & motivation for engaging with programme - 20 responses</p> <p>Post-workshop feedback surveys - 35 responses</p> <p>Nov 2022 quick review survey - 17 responses</p> <p>Nov 2022 interviews - 3 patients</p>	<p>Motivations for engagement include distraction from symptoms; peer support; better concentration</p> <p>Patients benefiting from connecting with others; brain stimulation; learning new skills; inclusive/supportive atmosphere</p> <p>Energy levels remain limited; other demands of life in conflict</p>
YEAR 2 Apr 2023 - Mar 2024	<p>Oct 2023 - quick review survey - 12 responses</p> <p>July 2023 - co-production 'Creative Huddle' event</p> <p>March 2024 - programme review survey - 21 responses</p>	<p>Participants reporting most significant impacts around improved mood, increased confidence and enjoyment of creative activities - with impacts now extending beyond the workshops</p> <p>Seated yoga seen as accessible, adaptable and beneficial</p> <p>Creative writing workshops requested</p> <p>Physical health impacts - better breathing; improved mobility/coordination; better sleep</p> <p>Mental health impacts - peer support/social connection; empowerment; acceptance; reduced anxiety; accomplishment</p>

Physical health

Due to the nature of long covid it is problematic to attribute improvements to any physical symptoms solely to participation in this programme. However, within qualitative accounts some patients do report perceived specific causal links between participation in Creative Space activities and improvements in aspects of their physical health. These include:



Views around how taking part impacts levels of tiredness and fatigue vary, with some participants reporting feeling more energised after activities, and some feeling energy levels depleted. In general, participants have felt that attending in-person events has been positive even in encouraging them to leave the house and go out.

“Huge difference! I feel alive! Included! Thrilled!”

“I love it but with travelling and activity I can have several days afterwards where I can do very little or nothing for a few days afterwards. It does make me feel more relaxed.”

“The difference between before and after the [seated yoga] session is remarkable. The sessions leave me feeling relaxed, refreshed and ready for the weekend ahead.”

“Breath and stretching exercises have eased stiffness and improved my sleep pattern.”

“Has relieved some pain symptoms and helped with vocal problems resulting from excessive coughing.”

“My hand skills are up and down but progress is there.”

“Physically having to attend has increased my exercise.”

“Allows me to exercise gently and safely while seated. My mobility is poor but I am still flexible. Having regular sessions is helpful.”

“The yoga allows me to find techniques for breathing and relaxing.”

Mental health

Within qualitative evidence gathered over the course of the programme, patients report significant improvements in their mental health that in many cases they attribute specifically to their participation in this programme. Impacts include:



“I have seen a massive improvement in my mood since connecting with others during the art cafe sessions. I feel so happy afterwards and the sessions are relaxed and set at a good pace.”

“It has improved my wellbeing, decreased my social anxiety which was a big issue for me and increased my confidence in social situations.”

“It has improved compromised social skills and also given me the means to manage symptoms. It has proved a useful distraction from daily challenges.”

“Being able to access online allows me to join a group independently and keep my independence rather than rely on someone to take me to a physical class.”

“The art cafe with Marie and the Cohere team has been instrumental in significantly improving my mental health.”

Participants have also expressed that taking part in various creative activities has encouraged them to use their brains differently, which has had a positive impact on their ability to focus and concentrate. They feel useful and empowered to have acquired new skills, and feelings of accomplishment when creating artworks.

“It was nice to use a different bit of my brain creatively and feel I had succeeded with something as I experience a lot of cognitive problems post covid.”

“I loved the drawing and being challenged to think creatively!”

“I felt my concentration improve even if it is a fraction of the time.”

“It was interesting to look at an object in a different way and learn a new skill”

Quality of life

Perhaps one of the most profound impacts of the programme is its role as a 'safe space' in which patients can connect with people experiencing similar challenges, finding peer support and empathy. This in turn has helped them adapt to and accept their 'new life' living with a long-term health condition. This has not been a conscious focus of the workshop sessions, but a phenomena that has occurred naturally and organically over time. As a result of the programme, a large group of participants have formed a WhatsApp group who meet independently and provide support for each other. New skills have helped participants feel accomplished, useful and armed with additional wellbeing tools for self management of their health conditions.

"Your sessions are the only place I've ever felt truly able to be myself around people who fully understand my condition. It's a magical experience."

"Having the opportunity to meet others with long covid and other chronic illnesses has been invaluable. I have made some amazing friends who truly understand what it's like to live with a chronic illness, I never need to explain my symptoms and that's liberating."

"Meeting and chatting with other people suffering has made me feel less alone."

"It has made me feel not so alone with my condition and cheered me up."

"It has made a huge difference being around people who truly understand and experience things so get what it's like daily living with Long Covid and other illnesses. Being able to support each other and chat openly as we've got to know each other over the last few months has made my mental health better than it's been for a while as I learn to accept the new me."

"I want to thank you all for these sessions, it's been a real surprise to enjoy them so much and great to meet other people who get what living with long term health issues and long covid. It's the first time I've met anyone face to face who has long covid which is mad, all these months on from diagnosis. It has really helped to share and know it's not just me out there in Suffolk. It has also done my mum a world of good too and even my Dad indirectly - as he is getting his paints out regularly now as well."

"Marie runs fun and relaxed art sessions that are perfectly balanced and delivered for people with long term conditions. She creates such an amazing and welcoming atmosphere, encourages our creativity and often sits with those who need a chat or are struggling in some way. I could not be happier that I found this wonderful group of people and I hope they continue to be able to deliver these art cafe sessions."

Learning

- Regular engagement in creative activities can be effective in supporting recovery from long covid, particularly around addressing mental health and quality of life of patients.
- Buy-in from clinical teams has been essential for recruitment and engagement of patients to the Creative Health programme. Co-production and training events have supported this.
- Creative activities can be tailored to stimulate cognitive function which may have positive impacts on brain-fog symptoms, and there is potential to explore the impacts of this further in both practice and research.
- Specific arts-health expertise and an inclusive ethos is key in nurturing a safe environment which encourages the natural development of social connections, creative skills.
- More medicalised language in communication and promotion of the programme has legitimised its status as a complimentary element of treatment for long covid.
- A reflexive and co-productive approach to programme design ensures that delivery meets the changing needs of patients.
- The majority of Creative Space participants identify as female - there is work to be done to include more male-identifying participants.
- A positive experience of a creative health programme such as Creative Space can encourage both further participant in arts and cultural activities and also the use of creativity as a wellbeing tool in the self-management of health challenges.

“I consider myself really fortunate to have come across Cohere....it's really changing my life!”