

# BMJ Open Acceptability and feasibility of a theatre-based wellness programme to support people living with long COVID: a single-arm feasibility study

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**To cite:** Burton A, Bone JK, Lawrence-Lunniss K, *et al.* Acceptability and feasibility of a theatre-based wellness programme to support people living with long COVID: a single-arm feasibility study. *BMJ Open* 2024;**14**:e083224. doi:10.1136/bmjopen-2023-083224

► Additional supplemental material is published online only. To view, please visit the journal online (<https://doi.org/10.1136/bmjopen-2023-083224>).

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<https://doi.org/10.1136/bmjopen-2023-083224>).

Received 14 December 2023  
Accepted 12 June 2024



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## ABSTRACT

**Objectives** To determine acceptability and feasibility of a theatre-based wellness programme to support the health and well-being of people with long COVID.

**Design** Single-group, repeated-measures feasibility study.

**Setting** Community centre and online.

**Participants** Adults with diagnosed long COVID experiencing breathlessness, pain and/or loneliness.

**Intervention** Six-week participatory creative programme delivered to one online and one in-person group facilitated by movement, voice and drama consultants using breathing, visualisation, singing, poetry, storytelling and movement exercises.

**Primary outcome measures** Programme acceptability and feasibility measured via uptake, reasons for non-attendance and barriers to engagement.

**Secondary outcome measures** Feasibility of recruitment and data collection procedures measured through proportion of missing data and follow-up rates, mechanisms of action of the programme identified through qualitative interviews, changes in mental health, well-being, quality of life, loneliness, social support, fatigue, breathlessness and post-COVID-19 functional status at 8-week follow-up.

**Results** 21 people expressed interest in participating, 20 people took part in the programme, 19 completed baseline and 16 completed follow-up assessments. Participants attended an average of 4.8 of 6 sessions (SD=1.5, range 2–6). Exploratory analyses demonstrated significant improvements in self-rated health (t-test mean difference=0.12, 95% CI=0.00, 0.23, p=0.04) and chronic fatigue symptoms (mean difference=-3.50, 95% CI=-6.97, -0.03, p=0.05) at 8 weeks. Key mechanisms of action that supported health and well-being included: increased sense of community, illness acceptance, experiencing joy, increased confidence in managing everyday life, increased ability to relax and reconnection with previous identity. Barriers to engagement included: activities being outside of the participant's comfort zone, ongoing long COVID symptoms, emotional consequences of sharing experiences and connectivity and connecting online.

**Conclusions** A 6-week theatre-based programme was perceived as acceptable to most participants and resulted in some positive psychosocial impacts. The findings provide a rationale for supporting the ongoing development

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study used a mixed-methods design to gain a rich insight into participant experiences.
- ⇒ We established the feasibility of including a range of primary and secondary outcome measures in a trial of this intervention.
- ⇒ No causal associations can be inferred between the programme and outcomes as there was no comparison group.
- ⇒ The sample size was small, and the follow-up period was 8 weeks, meaning any longer-term health benefits of participating in the programme are unknown.

and scale-up of this and related arts programmes to support people living with long COVID.

## INTRODUCTION

Long COVID (also termed post-acute COVID-19 syndrome) is a multisystem condition, causing a wide range of frequently severe and disabling symptoms.<sup>1–3</sup> With over 65 million people estimated to have long COVID globally,<sup>4</sup> it has rapidly become a major public health challenge.<sup>5,6</sup> As of March 2023, approximately 1.9 million people (2.9% of the population) were estimated to be living with long COVID in the UK alone.<sup>7</sup> The underlying pathological processes causing this condition are not yet clear but are thought to include direct impacts of the virus, immune system malfunctions, inflammatory damage and post-critical illness sequelae.<sup>4,8</sup> People living with long COVID commonly experience biological, psychological and social impacts, all contributing to reduced quality of life.<sup>3,9,10</sup> Long COVID is a heterogeneous condition, with multiple organ systems potentially affected; previous research has identified tens or even hundreds of symptoms.<sup>11,12</sup> For example, cardiorespiratory symptoms including breathlessness,

palpitations and chest pain, and neurological features including anosmia and cognitive processing difficulties or 'brain fog' are common. For many people, autonomic dysfunction and severe fatigue are dominant symptoms.<sup>13</sup>

There is extensive evidence that arts engagement is linked to improved physical and mental health<sup>14</sup> including the prevention and management of depression,<sup>15</sup> cardiovascular disease<sup>16</sup> and enhanced well-being.<sup>17 18</sup> Similarly, physical activity, which is often a key component or 'active ingredient'<sup>19</sup> of art forms such as dance or theatre, can improve cardiovascular health,<sup>20</sup> enhance functional capacity, quality of life and mood,<sup>21</sup> and reduce depression.<sup>22</sup> Arts activities involve a range of other health-promoting active ingredients, including creativity, cognitive stimulation, sensory activities and social interaction<sup>14 19</sup> and are therefore well placed to provide support to people living with complex and chronic health conditions. The INgredients iN ArTs in hEalth (INNATE) theoretical framework suggests that active ingredients of creative health interventions need to incorporate programme design and content alongside the broader social and contextual factors involved when people engage in creative health.<sup>19</sup> It is important to understand how these ingredients impact our health through their activation of a range of health-enhancing mechanisms which have been theorised by the Multi-Level Leisure Mechanisms Framework as psychological (eg, improved emotional regulation), biological (eg, reduced stress hormone levels), social (eg, reduced loneliness) and behavioural (eg, increased physical activity) processes,<sup>23</sup> so that arts programmes can be developed and tailored to meet the needs of specific populations and health challenges.

Evidence-based interventions for people with long COVID are currently lacking. Clinical guidelines are predominantly based on expert opinion, and advocate personalised, holistic approaches to support recovery.<sup>24 25</sup> Holistic arts-based interventions have shown promise to help support the health and well-being of people with long COVID; however, research is still in its infancy. A small pilot study found that a 10-week online singing programme improved breathing, fatigue and pain symptoms.<sup>26</sup> Only one clinical trial has been conducted and demonstrated that the English National Opera's online Breathe Programme involving 6 weeks of singing techniques and breathing exercises improved health-related quality of life and breathlessness when compared with usual care.<sup>27</sup> The evidence base for multifaceted creative health programmes suggests that theatre programmes can also support psychological well-being and quality of life among adults with chronic conditions<sup>28</sup> and people living with mental health problems by supporting a change in identity<sup>29</sup>; however, these approaches have not been tested specifically with people living with long COVID. These studies suggest that alternative creative approaches to long COVID symptom management should be further explored because while they may be unlikely to impact the (so far partially characterised) pathophysiological

cause of the condition, they may have a role in supporting the psychological and social aspects of living with long COVID and provide practical tools to help manage physical symptoms.

The aim of this study was therefore to determine the feasibility and acceptability of a theatre-based wellness programme for supporting the health and well-being of people with long COVID. The specific objectives were to:

- ▶ Explore programme acceptability via programme uptake, attendance rates, reasons for non-attendance and understanding barriers to engagement.
- ▶ Pilot recruitment and assessment processes for future larger-scale studies on arts-based programmes for long COVID.
- ▶ Explore mechanisms of action of the programme and assess the impact of the programme on health and well-being outcomes.
- ▶ Compare health and well-being outcomes and experiences of those participating in the programme online and in person.

## METHODS

### Sample

The sample size was determined pragmatically and was capped at the maximum number of people who could be supported during the programme delivery period with the resources available. Participants were recruited to the programme by community programme staff at the Old Vic, an independent not-for-profit theatre based in South London using three approaches: (1) advertising the programme on the Old Vic website and social media channels, (2) via existing contacts with researchers and clinicians who had informed the development of the programme, and (3) the Old Vic Education and Community team shared information about the programme with long COVID clinics in London. Participant inclusion criteria were: aged 18 years and above, a diagnosis of long COVID, and receiving assessment and support of self-referral from a clinician who deemed them suitable to participate in low-intensity physical activity with no medical contraindications. Participants also had to be experiencing at least one of the following: breathlessness, mild to moderate pain, and/or isolation or loneliness due to long COVID.

### The long COVID wellness programme

The Old Vic's long COVID wellness programme was a 6-week participatory creative intervention delivered by movement and voice consultants and a drama therapist and developed in consultation with health practitioners and people experiencing long COVID. The aim of the programme was to support well-being, fatigue and muscle and body pain. The group setting with other participants experiencing long COVID aimed to tackle feelings of social isolation or loneliness often associated with the condition.

Programme sessions took place between March and April 2022 and each session lasted approximately

90 minutes, including 15 minutes for introductions and opening the session and 15 minutes for closing. Each session consisted of three core activities of 15–20 minutes focused on movement, breathing, voice and/or theatre techniques. Activities included facilitator-led breathing exercises, visualisation, group singing and sound imagery, storytelling through sound and rhythm, movement exercises and poetry. The programme was delivered to two groups of 10 participants, one online via Zoom and the other in person in a community centre. Sessions were provided free of charge, and travel (to the in-person sessions) and consumables (eg, journals to document experiences of the programme) were reimbursed if needed. Further details of the programme have been published elsewhere.<sup>30</sup>

### Patient and public involvement

People experiencing long COVID, clinicians, movement and voice theatre practitioners and researchers were consulted in focus groups to inform the design and content of the long COVID wellness programme. Patients and the public were not involved in the design or conduct of the research procedures.

### Research procedures

All participants who signed up to take part in the programme were asked if they would be willing to take part in the evaluation. Participants could take part in the programme without taking part in the evaluation. A member of the Old Vic Education and Community team explained the study element to participants and asked if they would be happy for a researcher to contact them with further information. Those who agreed were then sent a participant information sheet and link to an electronic consent form via email by a researcher (AB) and encouraged to get in touch with AB if they had any questions. Once the signed consent form had been received, AB then contacted the participant to arrange the baseline assessment. Demographics and questionnaires were administered by AB who asked participants the questions and recorded their responses. All assessments were conducted over Microsoft Teams video call or by telephone in March 2022 up to 2 weeks before the participant attended their first programme session. Participants were then contacted again at the end of the programme (8-week follow-up) and the questionnaires were repeated using the same administration procedures. All follow-up questionnaires were completed in May 2022.

Participants could also take part in an optional qualitative interview about their experiences of taking part in the programme. This was either the same day as the follow-up assessment or on another day after the assessment (depending on participant preference). All qualitative interviews followed a semistructured topic guide. Participants were asked about whether they found the programme enjoyable and beneficial for their symptoms (and why) as well as any barriers or facilitators to engagement. Consent was obtained to audio-record interviews.

Audio-recordings were then sent to an external University College London (UCL)-approved company for transcription. All interviews were completed in May and June 2022.

All data were uploaded for analysis to the UCL Data Safe Haven, a secure data storage system that meets the requirements of the National Health Service Data Security and Protection Toolkit and International Information Security standard 27001. Participants were each assigned a unique identifier and quantitative data from the questionnaires were then inputted into an Excel spreadsheet by AB and checked for accuracy by JKB. Further data management and quantitative analyses were then performed using pseudonymised data in Stata V.17.<sup>31</sup>

### Measures

Participant demographics, socioeconomic status and COVID-19-related information and symptoms were collected at baseline.

Mental health and well-being were assessed at baseline and 8-week follow-up with questionnaires validated for use in similar adult populations. All measures had good internal consistency at baseline and follow-up (Cronbach's alpha ranging from 0.68 to 0.97, online supplemental table 1). Generalised anxiety symptoms were measured using the Generalized Anxiety Disorder Assessment-7,<sup>32</sup> with higher scores indicating more symptoms (range 0–21). Depressive symptoms were measured using the Patient Health Questionnaire-9,<sup>33</sup> with higher scores indicating more depressive symptoms (range 0–27). The Warwick-Edinburgh Mental Wellbeing Scale was used to measure mental well-being,<sup>34</sup> with higher scores indicating greater positive mental well-being (range 14–70). Loneliness was measured with the three-item University of California, Los Angeles (UCLA) Loneliness Scale,<sup>35</sup> with higher scores indicating greater loneliness (range 3–9). The Medical Outcomes Study Social Support Survey measured social support,<sup>36</sup> with higher scores indicating greater perceived social support (range 2–10).

The Post-COVID-19 Functional Status Scale measured functional limitations in usual activities at home or at work as well as changes in lifestyle.<sup>37</sup> Participants selected a grade indicating how much they were affected in their everyday life by COVID-19, ranging from no functional limitations (0) to severe functional limitations (4). The five-level EQ-5D measured participants' self-rated health,<sup>38</sup> with a health state index calculated using the English Devlin value set (V.1.1), which could range from less than 0 (death or as bad as death) to 1 (full health). Participants also completed the EuroQol Visual Analogue Scale (EQ VAS), rating their current health on a vertical VAS with 0 representing the worst imaginable health and 100 the best imaginable health. Dyspnoea (shortness of breath) was measured with the Dyspnoea-12,<sup>39</sup> with higher scores indicating more severe dyspnoea (range 0–36). The Nijmegen questionnaire measured symptoms associated with dysfunctional breathing patterns,<sup>40</sup> with higher scores indicating more severe respiratory distress and dysfunction (range 0–64). Chronic fatigue symptoms



(CFS) were measured using the Fatigue Assessment Scale, a 10-item measure with higher scores indicating more severe fatigue (range 10–50).<sup>41</sup> The DePaul Symptom Questionnaire Post-Exertional Malaise was used to measure post-exertional malaise (PEM).<sup>42</sup> Frequency and severity of five myalgic encephalomyelitis (ME) and CFS symptoms were rated on a 5-point Likert scale (0–4). A rating of 2 or more on both severity and frequency for one or more items was indicative of PEM. An additional five items measuring symptoms after mental or physical activity were used to indicate a diagnosis of ME and/or CFS.

### Statistical analyses

Participant characteristics were summarised at baseline to provide an overview of the sample. We then tested whether there were differences in the characteristics of those who chose to participate online versus in person using t-tests for continuous variables and  $\chi^2$  tests for categorical variables. For all analyses, we used  $p < 0.05$  to indicate statistical significance, but report findings based on the strength of the evidence (continuous p values and 95% CIs).

Acceptability of the programme was assessed by participant take-up and retention. We reported the range and average number of sessions attended and summarised the reasons for not completing the intervention. We then compared programme acceptability across the intervention modes (online vs in person) using a t-test for the number of sessions attended.

Feasibility of recruitment and research procedures was assessed by the length of time needed to recruit 20 participants and where they found out about the programme, as well as the proportion of participants who completed follow-up measures and the amount of missing data at baseline and follow-up.

Measures of mental and physical health and well-being were summarised at baseline and follow-up. All quantitative analyses were performed using Stata V.17.<sup>31</sup>

### Supplemental analyses

In exploratory analyses, we tested whether there was any indication of change in the secondary outcome measures over time, testing the difference in health and well-being scores between baseline and 8-week follow-up. Our aim was to identify suitable measures for future larger evaluations of this intervention. As this feasibility study was not sufficiently powered to robustly evaluate the intervention, these exploratory analyses are presented as online supplemental materials. For continuous outcomes, we used paired sample t-tests to explore whether there was evidence for differences across time points (follow-up vs baseline) (online supplemental table 2). For binary outcomes, we used McNemar's exact test (online supplemental table 2). These tests were chosen as the most appropriate and comparable approaches for testing changes within individuals over time for continuous and binary outcomes, respectively. For paired t-tests, we

assumed that participants were independent and checked that outcomes were approximately normally distributed. McNemar's exact test assumes that both variables have two categories, with participants only being members of one outcome group (ie, had vs did not have PEM). Due to the small sample size and minimal missingness (max  $n=4$ ; online supplemental table 5), we used listwise deletion to handle missing data.

To explore whether any change in outcomes differed according to the way in which the intervention was delivered, we repeated these analyses separately for the online and in-person groups (online supplemental table 3).

### Qualitative analysis of interviews

Interview transcripts were checked for accuracy against the audio-recordings by AB, deidentified (removing mention of specific names or places to maintain participant confidentiality) and imported into NVivo V.12 software for data management. An inductive thematic analysis was conducted<sup>43</sup> to identify potential mechanisms of action of the programme and to explore barriers to engagement in the programme. Two researchers (AB and KEJP) independently read through, familiarised themselves with and subsequently discussed two of the transcripts, noting meaningful fragments of text and labelling initial codes that responded to the research aims. AB then entered these initial codes into NVivo and coded the remaining transcripts, developing new codes based on the data and allocating existing codes to fragments of text within the transcripts. Codes were then organised into groups of similar topics that elucidated either a potential mechanism of action of the programme or a barrier to engagement. These topic groups were then used to inform the development of preliminary and final themes. Ongoing discussions took place between AB and KEJP to sense check the developing and final themes.

## RESULTS

### Intervention acceptability

21 individuals expressed an interest in taking part in the long COVID wellness programme, 20 (95%) participated and 19 (90%) completed the programme. One individual was no longer contactable after their initial expression of interest and one participant stopped attending the programme from session four onwards due to work commitments. Participants attended an average of 4.8 sessions (SD=1.5, range 2–6), with 55% of participants completing all six sessions. On average, in-person participants completed 5.1 sessions (SD=1.5) and online participants completed 4.5 sessions (SD=1.5). However, this difference was not statistically significant on a t-test (mean difference=0.60, 95% CI=-0.82 to 2.02,  $p=0.39$ ), indicating that there was little difference in session completion by intervention delivery mode. Reasons for missing sessions included work commitments, holidays, feeling too fatigued or unwell, testing positive for COVID-19 or living with someone who had tested positive

for COVID-19. One participant began attending in week 2 as they signed up for the programme after the first session had been delivered.

### Participant characteristics

Participants were aged 23–74 years (mean (M)=45.32, SD=13.51). The majority were female (84%), white British (63%), never married (42%) and highly educated (37% had postgraduate qualifications). Regarding their COVID-19 and long COVID status, 68% reported having a case of confirmed COVID-19 identified through a positive test, 11% had been hospitalised for COVID-19 and 42% reported being unable to work due to illness. On average, participants reported experiencing 12 (SD=2.5) long-term symptoms, including a cough, headache, shortness of breath, sore throat and difficulties swallowing, fatigue, muscle pains/weakness, inability to concentrate, and changes in mood, anxiety or depression.

Nine participants (45%) participated in the intervention in person and 10 (50%) online. One participant (5%) initially expressed a preference for in-person attendance but subsequently attended four in-person and two online sessions and was classified as attending in person for the analyses. The only significant difference between participants attending the intervention in person and online was their age (t-test mean difference=14.81, 95% CI=3.66 to 25.96,  $p=0.01$ ). Participants who attended in person (M=53.11, SD=10.65) were older than those who attended online (M=38.30, SD=12.21). No other characteristics differed between groups (online supplemental table 4).

### Feasibility of programme delivery and research procedures

All potential participants signed up to receive the programme within a 3-week period. The main sources for finding out about the programme were via long COVID clinics, general practitioners or other health practitioners and from friends or partners (table 1).

Of the 20 participants who took part in the programme, 19 (95%) consented to the evaluation and completed baseline measures (one person was too unwell with COVID-19 to take part in the research) and 16 (80%)

participated at follow-up. Of the three people who did not complete follow-up, one did not give a reason, one was not contactable and one declined due to missing several programme sessions because of COVID-19 reinfection and feeling that any health changes would not be attributable to the programme. Most study measures were completed by all participants (online supplemental table 5), with the exceptions of household income (n=4 missing), PEM (n=1 missing as the participant reported not being able to exercise) and social support at follow-up (n=1 missing as the participant became upset when completing this measure).

Participants were also asked what motivated them to sign up for the programme. Reasons included (1) to meet other people with long COVID and share lived experiences, (2) to get help in the absence of formal support from healthcare services, (3) to learn new strategies for managing symptoms, and (4) to engage in specific activities offered by the programme including breathing, movement exercises and creative activities.

### Supplemental analyses: change in outcomes

At baseline, participants reported moderate functional limitations (M=2.94, SD=0.52), poor health (self-rated health index M=0.56, SD=0.24 and VAS M=47.89, SD=16.21), respiratory distress and dysfunction outside of the normal range (M=29.47, SD=8.71) and relatively severe CFS (M=39.26, SD=7.51). Nearly all participants (94%) had PEM, although none had scores indicating ME or CFS (online supplemental table 1).

Examining the measures of physical and mental health descriptively at follow-up, there were improvements in all outcomes, including decreases in generalised anxiety and depressive symptoms, loneliness, shortness of breath, respiratory dysfunction, and CFS and increased mental well-being, social support and self-rated health (online supplemental table 1). In exploratory paired sample t-tests, there was only evidence for an increase in the self-rated health index and a decrease in CFS (online supplemental table 2). To explore whether any change in outcomes differed according to the way the intervention was delivered, we repeated these analyses separately for the online and in-person groups (online supplemental table 3). Although these analyses included a small number of participants, the overall improvements in outcomes appeared to be driven by larger changes in the in-person group than online.

### Mechanisms of action for improved health and well-being

During interviews, participants were asked how and why the programme supported their long COVID symptoms. Six key social and psychological responses to the programme were described that facilitated a change in health or well-being. Those participating in person articulated a wider range of potential mechanisms than those participating online; however, there were some shared experiences across both groups. Key mechanisms

**Table 1** Referral sources for the long COVID wellness programme

Source	N (21)
Long COVID clinic	5
GP or other healthcare practitioners	4
Word of mouth	4
The Old Vic's social media	3
Previous involvement with an Old Vic project	2
Long COVID Facebook group	1
Link worker/social prescriber	1
The Old Vic's mailing list	1
GP, general practitioner.	

are summarised below with supporting quotations from participants used to illustrate the findings.

#### Increased sense of community and bonding

Both groups described the sense of community established between participants and facilitators as important for improved well-being. This was achieved through participation in shared creative activities, collective breathing/movement exercises and being able to share personal stories of symptoms and illness within a safe and supportive environment. New relationships were formed between group members which contributed to a reduced sense of isolation and loneliness:

It's helped create hope that you can always be creative and collaborative with other people. What no one talks about, is the loneliness that this can create. Doctors don't refer you to other people who have long COVID to chat with. But just going, you're not alone, here's some mates you can have, is really important, we are still people. We're still social animals. So, another antihistamine isn't going to help, what does is creating a paper aeroplane, let's see where that takes you. (P31, in person)

#### A new feeling of acceptance

Participants described how the programme helped shift feelings of denial and frustration about the limitations that the illness had brought to their lives, to feelings of acceptance. This was achieved through structured drama and visualisation exercises where participants were guided to label their illness as a different character separate from themselves, as well as hearing others share their stories and experiences which helped validate their own illness experience:

I felt the work around acceptance (was) very helpful and we did a discussion around long COVID being this new tenant in our body, and this new character. There was one quote from <Facilitator> and she said that, "This is a rehearsal space for this new performance, this new way of being, and this new character that you might not have met before, but learning about it and through these activities, we can become more accepting," so I found that very helpful to look at the acceptance of an illness in a creative way. (P44, online)

#### Having fun and experiencing joy

Participants in both groups described the joy of engaging in creative activities and being able to play, be silly and have fun which in turn helped participants to build resilience:

I think that obviously the humour and art, being able to play helps you. Yes, helps your resilience, helps you dance things off a little bit. (P37, in person)

For some, being given permission to engage in playful activities was described as a welcome release from the daily reality of living with long COVID:

It just was the confidence and the being silly and not just being this serious sick person trying to figure out what the hell's wrong with them. (P30, in person)

#### Increased confidence in managing everyday life

Participants described an increase in confidence due to participating in the programme. For the in-person group, this meant that more activities felt achievable in everyday life such as being able to go out in public spaces again, despite ongoing symptoms:

I found myself just going off and going to a gallery, which I wouldn't have done otherwise. So, because I was in that situation, I would never have just gone and done that because I was too anxious about being in crowded places. I think it really did break the terror being in the world again. (P42, in person)

Through meditative exercises as well as being in a safe environment in which vulnerabilities could be shared, both groups described feeling more comfortable asking people for help outside of the group and sharing how they were feeling with others:

And being able to take up space and voice my needs currently. And as they change, feel confident to express what I need and not feel bad about it as much. And I think that's to do with finding breathing and grounding your breathing and the meditation as well, really checking in with myself. (P49, online)

The programme also gave participants new tools to use outside of the sessions which increased their ability to self-manage their symptoms:

I'm very conscious now of how I breathe and using those exercises. It hasn't changed my breathing, but I understand how to manage it better and how to consciously take care of myself in that way...It's affected the way I help myself to breathe which means I don't have to call the ambulance. (P36, in person)

#### Increased ability to relax, slow down and be present

Participants in both groups described learning the importance of relaxation and being present in the moment to help manage anxiety and stress caused by their illness through breathing, visualisation and mindfulness techniques:

The breathing exercises I found really helpful; I do those most days. Very good for relaxing and if I feel quite anxious or feel quite low, then I do those and it's also helped me with sleeping as well, which has been helpful. It has relaxed me a lot and I've been noticing- I think it's made my mindfulness practice a lot easier as well because I didn't realise I wasn't breathing in the best way, so learning that has



definitely helped with being mindful, and therefore helping the anxiety. (P34, online)

Participants talked about being given permission to slow down and that the programme helped them to tune into the limitations of their body and adjust their routines and behaviours accordingly:

And the other thing which quite surprised me is, I thought I was quite good at listening to my body- but I didn't always listen to it but at least I knew what it was saying. Sometimes I would choose to ignore it because I needed to do something for work, and I would push through. But I thought I was quite good at knowing what it was saying. But actually, through exercises we did, I found that, as much as I was putting on a brave face to the rest of the world, I was doing it even to myself. I wasn't always listening to myself as much as I should be. And I felt a lot more in tune with my body and I could understand a lot more where it was. (P50, online)

### Reconnection with their previous identity

For those in the in-person group who had previous experience of arts and creative engagement before COVID-19, participating in the programme enabled them to reconnect with this former creative identity and revisit their strengths.

It's reinstated the value of creativity and how much I can still do. How much it benefits me to do. Also, that I'm still hilarious. Being reminded of the stuff that you liked about yourself and the things that you're good at is really pleasing. (P36, in person)

The programme also enabled participants to reconnect with who they were before COVID-19 more broadly, regardless of creative identity:

I think a lot of it is just becoming yourself again, instead of just a long-COVID sufferer. I was just kind of traumatised by it. And just putting COVID aside, you know, just had - yeah a normal life. So it's great, from being in this odd place, and finding very little help from anything. So yeah it's made a huge difference. (P42, in person)

### Challenges to programme engagement

Participants were asked about whether they faced any barriers to engagement in the programme to help understand whether any potential adaptations might be needed for future programme delivery. Four barriers were identified and are summarised below with supporting quotations from participants.

#### Activities outside of my comfort zone

Some participants described feeling self-conscious when engaging in drama activities and felt that this part of the programme was outside of their comfort zone, especially when encountering the exercises for the first time:

On the whole, it was easy to engage. I think it was just what as individuals we're comfortable with. Or what we're not comfortable with. What's out of our comfort zone and some of that was making the noise of how COVID's making you feel. Doing a gesture to it. It just felt a little bit silly at times. (P41, in person)

While most of the in-person group were able to work through their discomfort as the programme developed, a small number of online participants continued to struggle with the drama elements throughout the programme, and for some, they were viewed as inappropriate:

I found the actor part of it, there was things like, think of a name for your condition, and then make a noise like the name you've thought of. I just found that excruciatingly patronising. Really, really difficult to engage in. I did try. But I just thought it was really inappropriate for a health condition like this. (P48, online)

#### Ongoing and fluctuating long COVID symptoms

For many participants, ongoing and fluctuating long COVID symptoms interfered with their ability to engage with some elements of the programme, from being able to get on public transport to attend in person through to difficulties concentrating on activities:

Sometimes I found it quite long, an hour and a half. For me I think an hour is better, but that's me because I am suffering so frequently still. So it was very tiring. And with the brain fog sometimes I found it hard to concentrate. So, when they were asking questions or there was feedback, sometimes I couldn't, it was getting muddled in my mind. (P32, online)

While the programme was experienced by some as energising, for others, the intensity and pace of the physical activities exacerbated their fatigue:

So, physically it was knacker. I was the only one who sat on a bean bag, everyone else sitting on chairs. I can't sit on a chair yet. But I really liked the breathing exercises. The physical exercises in theory were really nice but they were too much for me. (P36, in person)

#### Emotional consequences of sharing experiences with the group

Participants described their worries about and experiences of sharing their vulnerabilities with others in the groups. For some, this was a painful experience:

There were a couple of experiences...when you deal with this on a day-to-day basis, and the shortcomings that you have when you're usually on your own, (you) manage it. But when those shortcomings are in a public, social context, it can be quite emotional. You can get quite- it concretises your problems...So, the challenges were - my limitations being writ large in a social setting. (P36, in person)

Despite these difficulties, many participants acknowledged that the programme was designed to be an *openly vulnerable space* and that the environment felt safe and supportive:

And to have a safe space to feel all the emotions you are feeling without worrying about anyone's opinion as to whether or not you should be feeling those emotions. (P50, online)

#### Connectivity problems and connecting with others online

Online participants described connectivity problems, with particular issues around sound and noise control:

Yes, it just would cut out or it would be really loud and then you wouldn't be able to hear them speaking, or you wouldn't be able to hear the music at all. (P49, online)

While most participants described the benefits of meeting others online and described the group as a supportive community, a small number of participants also described difficulties communicating with one another or not feeling connected to the group, attributing this to the online format:

But the only element of doing it that way is I don't feel as connected. So, at the end where we had the choice to keep in touch with people I've said no because I didn't really feel, even though I understood it was nice to see other people's faces, that connection I didn't feel. (P32, online)

## DISCUSSION

This is the first known study to test the acceptability and feasibility of a 6-week theatre-based wellness programme for supporting the health and well-being of people living with long COVID. Our work adds to a small but growing body of literature on the feasibility and impact of arts-based interventions to support the well-being of this population, with previous research focusing on online singing and well-being interventions.<sup>26 27</sup> Retention in the research study and programme was high and improvements in health outcomes were observed which appear to have been greater in the in-person group compared with online delivery. Qualitative findings supported this observation, with in-person participants identifying more potential mechanisms of action for why the programme supported their health and fewer challenges to engagement compared with those participating online. Exploratory quantitative analyses found improvements in all health and well-being outcomes, although only differences in self-rated health and CFS were statistically significant. The lack of evidence for other outcomes may be because the study was not powered to detect effects of the intervention on these secondary outcomes. Reductions in loneliness and increased perceived social support (identified quantitatively) were supported through mechanisms

of increased sense of community and bonding, particularly in the in-person group, a new feeling of acceptance among group members with shared lived experience and increased confidence in sharing illness experiences with people outside of the group (identified qualitatively). Well-being as an outcome was supported through mechanisms of experiencing fun and joy and reconnection with a previous identity, while anxiety and fatigue outcomes were reduced through the programme's focus on relaxation and mindfulness. The programme also gave people tools to help manage physical symptoms such as breathlessness outside of the sessions.

Our research highlights the importance of flexibility and tailoring when designing and delivering arts-based programmes to meet individual health needs and preferences.<sup>44</sup> For example, we found that the average age of participants in the online group was younger (38 years old) than those attending in person (53 years old) suggesting that different formats might be needed to cater towards the needs and preferences of different age groups. There were also some opposing experiences of the programme among participants; most notably, while some participants felt energised, others experienced increased fatigue (however, outcome assessments showed overall significant improvements in fatigue). Some participants experienced the drama exercises as challenging and inappropriate, while others embraced and enjoyed them, which contributed to an increased sense of well-being. Providing clear information on programme content as well as presenting information on the hypothesised links between arts engagement and health outcomes and what the specific programme aims are in relation to health and well-being outcomes might help manage expectations and improve experiences for participants and healthcare services linked to creative health approaches.<sup>45 46</sup>

Almost half of study participants found out about the programme via a healthcare professional. This suggests a willingness to incorporate creative health interventions into clinical care pathways as a viable support option for people experiencing long COVID. Referral criteria for social prescribing should include people with long COVID to ensure that arts-based programmes are reaching them and to ensure they are embedded within health system–social prescribing referral pathways both within the traditional primary care link worker model and via healthcare professionals working with people in long COVID clinics. A further strength of the study was the inclusion of people who self-reported long COVID symptoms without needing to provide evidence of a positive swab test or antibody test confirmation of COVID-19 diagnosis. Many people were unable to access testing, particularly at the start of the pandemic, and have subsequently struggled to access support from more formal services such as long COVID clinics.<sup>10</sup> Alternative support is therefore specifically needed for this group of people.

Several limitations should be appreciated. Although changes in outcome measures suggested positive impacts, the single-arm design of the study means that we cannot



infer with certainty that the programme was effective. The study was not statistically powered for the quantitative outcome measures, and multiple measures were assessed. We therefore cannot make causal conclusions. However, as this was an exploratory study testing a novel and complex intervention with the potential to have an impact on a range of health and well-being outcomes, we wanted to ensure that a wide range of outcomes were explored to inform appropriate outcome measure selection in future research. Significant changes were observed in general health and fatigue scores, making them potentially appropriate primary outcomes in future larger-scale clinical trials. Additionally, the small sample was not representative of the population, so findings cannot be generalised from this context. Having used open publicity to contact potential participants rather than directly approaching people, it was not possible to calculate the recruitment rate as a proportion of people approached. However, participants were recruited reasonably quickly, and completion rates were high, suggestive of high levels of acceptability. Of the participants who finished the programme, three (16%) did not complete the study follow-up. Although the remainder of participants completed most outcome measures, this attrition should be considered in power calculations for future trials of this or similar programmes. Additionally, when considering potential confounders in future trials, household income was missing more data than other participant characteristics. Studies should thus consider how this question is framed, and whether alternative measures of socioeconomic status may be more acceptable to participants.

The results of this study are largely in keeping with previous research into related interventions; shared lived experience among creative health programme participants has been identified as important for increasing feelings of social support.<sup>47 48</sup> Engaging in creative health programmes has been found to contribute to a renewed sense of identity,<sup>49</sup> increase confidence in communicating needs and experiences to others<sup>47</sup> and reduce feelings of loneliness and social isolation.<sup>50 51</sup> Some of the barriers to engagement identified by a minority of participants in the current programme appear to be novel findings such as feeling self-conscious when engaging in drama activities and the emotional consequences of sharing experiences within a group. This could be because theatre-based programmes have not been previously tested with this population and could also be due to concerns around sharing illness experiences and vulnerabilities in response to previous negative reactions and a lack of understanding from healthcare professionals, family and friends.<sup>10</sup> The intervention appears to be well received by participants. Perceived impacts were generally positive, and predominantly psychological and social, while also providing tools to help manage physical aspects of the condition. As with previous work into singing-based interventions that target breathing for people with long COVID,<sup>26 27</sup> there may be a small impact on symptoms; however, the learnt coping strategies appear to be useful for some participants in modulating the experience of the condition. Prominent psychosocial impacts echo the broader body of research on creative health interventions,<sup>14</sup>

though the small scale and exploratory nature of this study means comparisons and conclusions should remain cautious.

## Conclusion

Long COVID is a common and often disabling condition with a range of biological, psychological and social impacts. Evidence-based management strategies are lacking. Creative health interventions may have a role in supporting the psychological and social impacts of long COVID. Our findings suggest this 6-week theatre-based programme is perceived as acceptable with a range of potential positive psychosocial impacts experienced by participants. These findings could inform a larger clinical trial on creative health programmes and support the ongoing development of this and related programmes for people experiencing long COVID.

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**Acknowledgements** We would like to thank all of the participants who took part in this research study

**Contributors** AB, KL-L and KEJP designed the study. AB was the lead investigator and guarantor of the study and was responsible for data collection and qualitative data analysis. JKB performed the quantitative data analysis. All authors contributed to manuscript drafting, editing and revision, read and approved the submitted version.

**Funding** The long COVID wellness programme was funded by MariaMarina Foundation, (grant number: not applicable); however, this research received no grant from any funding agency in the public, commercial or not-for-profit sectors. KEJP is funded by the National Heart and Lung Institute Clinical Lecturer Programme (grant number: not applicable).

**Competing interests** KEJP has received speaker fees from Chiesi for non-promotional educational presentations.

**Patient and public involvement** Patients and/or the public were involved in the design of the intervention studied in this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by the UCL Ethics Committee (project ID: 6357/003). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplemental information. Raw data are available in the form of participant quotations and the interview topic guide upon reasonable request.

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