



THE STROKESTRA® COMMUNITY PROGRAMME: RESEARCH REPORT

DR. ELAINE KING

DR. GRAZIANA PRESICCE ROSIE DUNN

DR. HELEN PRIOR CAROLINE WHITE



sempre:

Society for Education, Music
and Psychology Research

Executive Summary



This research project explored the effectiveness of a pioneering stroke rehabilitation programme called the STROKESTRA Community Programme (SCP). The SCP aimed to facilitate recovery in stroke survivors and to support their carers through orchestral music-making. Existing research and intervention studies indicate that music can be an effective therapeutic tool for stroke survivors; however, the SCP is a unique programme through its use of music group work with orchestral instruments.

The SCP was delivered by members of the Royal Philharmonic Orchestra (RPO) with assistance from volunteers, including University music students and community workers. The programme ran in “terms”, each comprising a series of music workshops culminating in a live public orchestral performance given by everyone involved in the programme (stroke survivors, carers, musicians and volunteers). All workshops and performances took place in community venues.

The rationale for the research project was to provide an independent evaluation of the SCP for the RPO. There were three aims: (1) to identify the different strategies required to **implement** the SCP, including potential barriers; (2) to investigate people’s **experiences** of participating in the SCP; and (3) to explore how leaders, musicians and volunteers **facilitated** the programme.

The overall objective was to evaluate the **effectiveness** of the SCP and to **develop guidance** for implementing and facilitating an arts-based rehabilitation programme in a community setting. The research adopted a multi-method approach using semi-structured interviews and observations, the key findings of which are presented in this report (for a full account of the research, see King et al., forthcoming).

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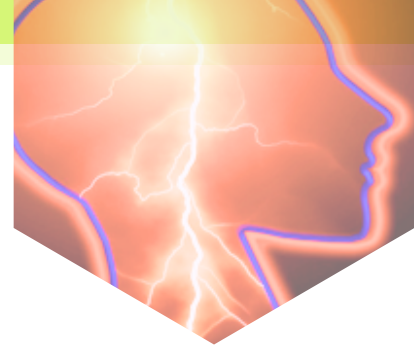
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1. CONTEXT: About Stroke

Stroke is a leading cause of mortality and disability (Feigin et al., 2022). It is associated with significant costs for health services, social care, patients and carers (Xu et al., 2018). Both stroke patients and carers may experience difficulties in adjusting post-stroke to new roles, relationships and challenges, the loss of social opportunities, contacts and activities, difficulties in leaving the home environment and managing in new environments; these may lead to isolation and boredom (Hawkins et al., 2017; Woodford et al., 2018; Denham et al., 2019; Wray et al., 2019). Further, maintaining independence and regaining “normal life” are reported as important by stroke patients, and a need to regain confidence has been identified (Hawkins et al., 2017; Mavaddet et al., 2018; Wray et al., 2019). The opportunity to meet and connect with peers experiencing similar challenges has been highlighted (Thomas et al., 2017; Denham et al., 2019). Carers (family and friends) can experience impacts on their own physical and emotional health and wellbeing, on their social networks, as well as experiencing emotional distress and difficulties in accessing information and support (Cecil et al., 2013; Denham et al., 2019). They also need support to enable them to manage the impacts of caring in their daily lives. Therefore, effective rehabilitation approaches are required to support recovery across a range of physical, psychological and social domains for both stroke survivors and carers.

Existing research in the field of stroke and neurological rehabilitation indicates that music can be used as an effective therapeutic tool for improving cognitive, motor and neurological functions as well as for promoting positive socio-emotional changes, such as mood and well-being, in stroke survivors (e.g. Zhang et al., 2016). The majority of studies adopt music listening activities as the principal form of therapy, including rhythmic auditory stimulation and melodic intonation, although selected projects use creative, practical and interactive music-making activities, such as rhythm and movement therapy (Thornberg, Josephsson & Lindquist 2014), group musical improvisation (Thaut et al. 2009) and group musical composition (Habron et al. 2013; also see <https://strokeodysseys.org/> and <https://www.interactstrokesupport.org/>). Less is known about the impact of music therapy for carers of stroke survivors, although there is growing emphasis upon joint, relationship-centred interventions for both stroke survivors and carers in healthcare research (Clarke et al. 2021).



2. CONTEXT: About STROKESTRA

STROKESTRA is a music-therapeutic programme designed by members of the Royal Philharmonic Orchestra (RPO) and clinicians from the Hull and East Riding Community Stroke Services (HERCSS) (see www.rpo.co.uk/rpo-resound/strokestra). STROKESTRA advances existing forms of rehabilitation in three novel ways:

- 1 it offers a creative and practical approach to stroke rehabilitation through group music-making with orchestral instruments;
- 2 it has a performance agenda which involves everybody playing together in front of a public audience at the end of each term;
- 3 it has an inclusive agenda because the programme is open to stroke survivors and their carers who play alongside professional musicians and community volunteers.

STROKESTRA was delivered in Hull (UK) from 2014 to 2023 in three distinct stages:

1 Pilot stage: this was delivered jointly by musicians from the RPO and clinicians from HERCSS. A service evaluation was provided by the delivery team (Nicholson, Rodio & Wilson, 2016).

2 Main stage (terms 1 to 4): this was delivered by the RPO and clinicians from HERCSS in two settings: community and in-patient. The community setting involved stroke survivors and carers living in the community and the in-patient setting involved stroke survivors in a nursing home who had experienced more recent strokes. The research team began an independent enquiry, but this stage was suspended early on due to the COVID-19 pandemic; insufficient data was collected to enable evaluation. The RPO conducted two terms in an online format before the main stage was terminated; this was not evaluated due to the exceptional delivery mode which was not expected to continue.

3 Community stage (terms 5 to 6): this was delivered only by the RPO without the support of clinicians and instead with volunteers (University music students and community workers). The revised programme was called the STROKESTRA Community Programme (SCP). The research team completed independent research about this stage, the findings of which are presented in this report. A summary of the project timeline is given in Table 1.

TERM	DATE	STAGE	RESEARCH ACTIVITY
Pilot	May to October 2015	Pilot	NO [internal service evaluation]
Term 1	November 2018 to March 2019	Main	NO [set up]
Term 2	June to September 2019	Main	NO [design/ethics]
Term 3a	January to March 2020	Main (suspended)	✓
Term 3b	November 2020 to February 2021	Main (online)	NO [not applicable]
Term 4	December 2021 to March 2022	Main (online)	NO [not applicable]
Term 5	May to July 2023	Community (SCP)	✓
Term 6	September to December 2023	Community (SCP)	✓

Table 1. STROKESTRA terms, dates, stages and research activity



3. RESEARCH: About the Project



3.1 Aims, Objectives & Questions

1

1st Aim (Implementing): to identify different strategies required to implement the SCP.

Research Question 1: How is the SCP implemented?

Research Question 2: What recruitment / training / logistical strategies are used?

2

2nd Aim (Experiencing): to investigate how stroke survivors, carers and facilitators experience the SCP.

Research Question 3: What are the experiences of stroke survivors and carers participating in the SCP?

Research Question 4: What are the experiences of people facilitating the SCP?

3

3rd Aim (Facilitating): to explore how musicians and volunteers facilitate the SCP.

Research Question 5: How do leaders, musicians and volunteers support stroke survivors and carers in the SCP?

The first objective was to provide **independent research** about the SCP, especially to consider its **effectiveness** as a music-therapeutic intervention. The second objective was to develop **guidance** for delivering an arts-based therapeutic programme in the community through identifying strategies based on the SCP, as well as examples of good practice.

3.2 Ethics Statement

The research team received ethical approval from the University of Hull Faculty of Health Sciences Research Ethics Committee on 5 May 2023 (Reference: FHS.22-23.69). Participants agreed to participate voluntarily through verbal or written consent with assurance of anonymity in any presentation of the data collected. All participants had capacity to consent to taking part and this was assessed informally following the Mental Capacity Act (2005) guidelines.

3.3 Design, Data Collection & Analysis

A **multi-method** approach was used to evaluate the SCP, which included interviews, observations and self-report measures (on wellbeing and recovery). The latter were collected from only some stroke survivors and carers as they covered very sensitive ground and many participants preferred to discuss these more freely; the resulting sample was too small to conduct meaningful statistical interpretations. This report focuses on the **interview** and **observation** data only which enabled nuanced and detailed insight into how the programme was implemented, experienced and facilitated. For each term, the following three steps were undertaken:

Step 1: Recruitment

Researchers **attended** the 1st and 2nd **workshop** of the SCP to share information leaflets about the research and to recruit participants. They also attended one of the final workshops to provide a further opportunity to recruit facilitators and to invite stroke survivors and carers to participate in an end-of-study interview only.

Step 2: Data collection

- Start of each term: **“pre-term” interviews** with stroke survivors/carers.
- During term: **observation** of one or two SCP workshop sessions.
- End of each term: **“post-term” interviews** with stroke survivors, carers and facilitators.

Step 3: Data analysis

- Transcriptions** of all interviews.
- Thematic Analysis** (Hseih & Shannon, 2005; Braun & Clarke, 2006) of all transcripts and observation reports through the use of the digital software NVIVO.

3.4 Participants

39 people participated in the research (see Table 2). The Project Leader (RPO) and Workshop Leader (RPO) were interviewed twice (one interview each in both Terms 5 and 6); all other participants took part in the research in one term only.

Stroke survivors (n=13; 8 males; 5 females) ranged in age from 20s to 80+ years. Carers (n=4; 3 males; 1 female) ranged in age from 70s to 80+ years. The musical experience among stroke survivors and carers ranged from novice to professional (e.g. band members, classical pianists, choir singers, music teachers). Some individuals previously pursued music as a hobby (e.g. self-taught instrumentalists), while others described a keen interest and appreciation of music through listening to it and attending live concerts.

TERM	ROLE	DATA
Term 5 n=22	13 Facilitators: 1 Project Leader 1 Workshop Leader 6 RPO Musicians 3 Music Students 2 Venue Managers	13 x post-term interviews
	8 Stroke Survivors	4 x pre-term & post-term interviews 4 x post-term interviews
	1 Carer	1 x post-term interview
Term 6 n= 17	9 Facilitators: 1 Project Leader 1 Workshop Leader 1 Primary Volunteer 2 Volunteers 3 RPO Musicians 1 Music Student	9 x post-term interviews
	5 Stroke Survivors	1 x pre-term interview 2 x pre-term & post-term interviews 2 x post-term interview
	3 Carers	1 pre-term interview 2 post-term interviews
TOTAL n=39		

Table 2. Summary of participants and data

Stroke survivors reported a wide range of health and other impacts as a result of their stroke. It should be noted, however, that they also informed the researchers about co-existing health conditions, which created challenges in identifying the exact cause of certain effects (that is, whether from stroke or another condition). Previous and other co-existing conditions included dementia, arthritis, diabetes, mental health struggles, cranioplasty and cancer. Whilst the nature and degrees of reported effects of a stroke varied with each individual, for the majority of participants the effects were life-changing (for a summary of the impact on stroke survivors, see Table 4). Participating carers also reported how they had been affected by their partner or friend having a stroke (for a summary of impacts on carers, see Table 3).

Impact	Reported Problems	Example
Emotional	<ul style="list-style-type: none"> increased apprehension adapting character to avoid upsetting partner impacted relationships 	<i>"It's changed my personality...because I had to refrain [...] from saying certain things that might upset [name]" (Carer 1).</i>
Loss of Employment	<ul style="list-style-type: none"> stop job 	<i>"I was also doing a lot of consultancy work. So I'd travel [abroad]...and that...that...stopped. Overnight" (Carer 2).</i>
Loss of hobbies & interests	<ul style="list-style-type: none"> stopping activities 	<i>"We have a caravan and we used to go...did a lot of hiking...that's just come to an end, you know you just can't do that" (Carer 4).</i>
New tasks	<ul style="list-style-type: none"> deal with new household tasks 	<i>"We've been married 54 years this year and he's never, never cooked before" (Stroke Survivor 13).</i>

Table 3. Summary of reported impacts of stroke on participating carers



IMPACT	REPORTED PROBLEMS	EXAMPLE
Physical <90% survivors	<ul style="list-style-type: none"> • mobility difficulties • pain • numbness or weakness of affected limb • affected vision • swallowing problems • hearing problems • headaches & seizures 	<i>"I have epileptic fits as well...but I was fit as well before me stroke...I played rugby all me life...they just come like that you, you haven't got no warning, no anything" (Stroke Survivor 4).</i>
Fatigue <60% survivors	<ul style="list-style-type: none"> • organise daily tasks around energy levels • afternoon nap needed • day of rest needed • side-effects of medication • co-existing medical conditions 	<i>"If I go out for a day...the next day I have to rest; because...physically and mentally, I can't cope with it" (Stroke Survivor 11).</i>
Emotional <90% survivors	<ul style="list-style-type: none"> • moods • shock • higher sensitivity to emotions • depression • frustration 	<i>"Me daughter...said to me "mum, you don't smile anymore". Well that...really broke my heart, cos [I've]...always been happy" (Stroke Survivor 13).</i>
Social <35% survivors	<ul style="list-style-type: none"> • feeling isolated • affected friendships • affected belonging to social circle (e.g. work colleagues or family) • stopped going out • stopped attending family events 	<i>"When you have a stroke everybody just forgets ya" (Stroke Survivor 1).</i>
Cognitive <75% survivors	<ul style="list-style-type: none"> • impact on memory • concentration difficulties • cognitive challenges (e.g. telling the time, naming objects, reading) • brain fog • inability to make quick decisions 	<i>"It can affect reading. I mean I can read a word completely wrong. [...] But then I know immediately that doesn't make sense so I then go back..." (Stroke Survivor 3).</i>
Communication <35% survivors	<ul style="list-style-type: none"> • speech problems (e.g. stuttered, slurred or slowing down) • voice becomes weaker with tiredness • conversation difficulties over the phone 	<i>"I have...trouble with my carer [...] you know, my voice kinda...trying to get out and it takes like ten/fifteen minutes for me to get out. It's just...my mouth and all that" (Stroke Survivor 8).</i>
Loss of Employment <30% survivors	<ul style="list-style-type: none"> • sudden stop to employment/volunteering work 	<i>"The work where I worked at wasn't set up for disabled people [...] So there was no way I could have gone to work [...] And basically I, I've just been sat at home" (Stroke Survivor 1).</i>
Loss of independence <60% survivors	<ul style="list-style-type: none"> • unable to drive • unable to walk far • unable to complete everyday tasks without assistance (e.g. cooking, showering, getting dressed) • concern if something goes wrong while carer is out 	<i>"I'm at a stage where I can't even dress myself. I can't tie my shoes. I can't use a knife and fork" (Stroke Survivor 10).</i>
Playing musical instrument <45% survivors	<ul style="list-style-type: none"> • slower at the instrument • not able to play at all 	<i>"I used to get spasms when my arm...so I couldn't hold a rhythm [...] which was quite upsetting. So...I put the guitar down and I didn't touch it" (Stroke Survivor 12).</i>
New hobbies & interests <30% survivors	<ul style="list-style-type: none"> • wheelchair-friendly activities • started slower-paced hobbies • started positions on different committees 	<i>"It's opened other doors [...] I like photography and I like music of course. So I can now have the time to look at things in a different way and hear things in a different way." (Stroke Survivor 10).</i>

Table 4. Summary of reported impacts of stroke on participating stroke survivors

4. RESULTS:

Key Themes

The key themes arising from the interview data were organised into categories according to the three pathway aims of the project: implementing, experiencing and facilitating (see Table 5).



Table 5. Summary of main themes in the SCP data

Key points relating to each of these themes (and their relevant sub-categories) will be given below with supporting quotes from participants extracted from the interview data. Keywords will be highlighted for emphasis. Participant quotes will be labelled according to the scheme in Table 6.

PARTICIPANT LABEL	EXPLANATORY NOTE
Stroke Survivor	A member of the community who had experienced a stroke recently or some time ago & was living in the Hull region
Carer	A family member or friend of the stroke survivor
Project Leader	RPO personnel
Workshop Leader	RPO creative practitioner who led the SCP sessions
Musician	RPO musician
Music Student	University music student (volunteer)
Primary Volunteer	Community worker (with background/experience in healthcare) who coordinated volunteers & liaised with the Project Leader from the RPO
Volunteer	Community worker (with background/experience in healthcare)
Venue Manager	Community worker at venue

Table 6. Participant labelling scheme



4.1 Implementing the SCP

4.1.1 Setting Up

Training: Training for the RPO musicians was **structured** and led by the workshop leader and project leader: *“it’s not something you would come and do without a couple of days of training”* (Musician 2). Facilitators undertook training at different stages of the SCP depending on which term they were to be involved in. Important information was also learned and shared through **ad hoc conversations** among facilitators and gained through **experience**: it was a *“very experiential-based learning”* (Workshop Leader); *“you just have to go and do it and then that’s the training”* (Musician 6); *“If I hadn’t been a physio and I hadn’t...done stuff like that before, then perhaps I would have needed some instruction”* (Volunteer 2).



Recruitment: The recruitment process (that is, the recruitment of stroke survivors and carers onto the SCP programme) **changed** over time from the pilot to term 6. For the SCP, the **Project Leader** led the recruitment process by getting in touch with different stroke support groups and stroke associations, although only a small number of participants were recruited from these groups. The **Primary Volunteer**, who had a background in healthcare, assumed a key role in supporting the recruitment process: *“we do rely on her...time to get initial referrals coming through...it would be difficult without that”* (Project Leader). Even though the maximum number of people that would be able to attend per session diminished as a result of the lack of clinical support in the SCP, stroke survivors from previous terms were able to return: *“we’ve had people who’d come back who did the original sessions in 2015...so that’s quite nice...cos obviously they still want to come back and enjoy it”* (Project Leader).

Places and Venues: The venue for workshops and performances changed across the different terms of the SCP. It was noted that the **choice of venue influenced people’s involvement in the programme** and this had the potential to break down barriers and increase accessibility: *“It is one of Hull’s most deprived areas. So when you think of an orchestra, you think of affluent people being able to afford the violin, violin lessons... they’re doing that [here]”* (Venue Manager 2). Venues were selected by considering participants’ needs, which included the following features:

- Large room, big enough to allow participants to sit in a circle;
- Comfortable temperature;
- Good light and ventilation;
- Kitchen/area available for refreshments and breaks;
- Plenty of seats and tables for instruments or cups;
- Good accessibility (car park, ramp, easy access for taxi drop off and pick up, single level venue, convenient location);
- Disabled toilets;
- Familiarity with the venue helpful to engage new recruits.



Motivation: Facilitators provided a variety of reasons behind their motivation to participate in the SCP, including interest in doing community work and music therapy (see Table 7). In particular, RPO musicians described the programme as “rewarding” and “liberating”. Music students volunteered to gain experience as part of University modules, while community volunteers were interested in helping others and engaging with music.

ROLE	MOTIVATION TO PARTICIPATE	EXAMPLES
RPO Musicians	<ul style="list-style-type: none"> • Interest and enjoyment in doing community work • Create variety in work • Connection with participants / audience • Liberating, spontaneous experience • Rewarding project • Programme reputation: heard good things about STROKESTRA 	<p>“Having that interaction with people can change their lives and enrich their lives in different ways [...] than the way that concerts can” (Musician 3).</p> <p>“I don’t want to just always be sitting on the stage and have this big gap between me and the audience” (Musician 3).</p>
Music Students	<ul style="list-style-type: none"> • Interest in music therapy • Part of a university module 	<p>“That’s my area of focus because I want to see how music can benefit people for health reasons” (Music Student 3).</p>
Volunteers	<ul style="list-style-type: none"> • Friendship with Primary Volunteer • More time available/retirement • Interest in helping others • Musical interest 	<p>“It was a way of...using my previous clinical skills as a physiotherapist and linking it in with my music interest” (Volunteer 2).</p>

Table 7. Motivations to participate in the SCP

4.1.2 Sessions

Structure and Activities: The SCP workshops included a range of music-making activities (see Figure 2). The structure of a **2-hour session** was typically divided into two parts with the first hour progressing from warm-up activities with physical exercises and conducted sequences to playing orchestral instruments. After a **break**, which provided an opportunity for participants to socialise with peers and with musicians, the remaining time involved playing different orchestral instruments and creating other pieces of music, including songs, “musical postcards” or familiar tunes.





Figure 2: Typical SCP music workshop activities

Practicalities: A number of practical aspects emerged from the facilitators' interviews and the researchers' observations that appeared to be important factors in the effective facilitation of the SCP:

- **Name badges** were made for everybody, so people could see and be reminded of each other's names;
- **Taxis** were arranged for stroke survivors and carers to get to and from the workshop venue. This provision helped to overcome transport barriers: *"I've lost my car and everything"* (Stroke Survivor 6);
- **Refreshments** were made available for breaks (tea and biscuits);
- People needed access to **ear defenders**, for anyone who may find sounds over-stimulating;
- **Instruments** had to be adapted so they could be used by survivors with an affected limb;
- **Musician numbers:** The number of RPO musicians in the sessions was critical so individual support could be provided as needed: *"You couldn't do it with just one musician"* (Musician 4).

Briefings: Facilitators held **regular briefings** and **debriefings** at the start and/or end of workshops, which allowed them to remain up-to-date with particular situations or needs from individuals, to share observations as well as to gain a (flexible) overview of what the session might entail: *"before it starts...he will tell us his plan, but it doesn't always go to plan [laughs]"* (Musician 4). Debriefs also helped to tailor and shape future sessions: *"otherwise you're going in blind and you have no idea who you're working with and how to handle that...cos none of us are like trained clinicians"* (Musician 7). At the same time, **self-reflection** helped some musicians to improve upon their practice: *"I think as musicians we are very good at being self-critical [of] our own work and our own playing so...you're always looking for ways that you can make your own contribution better"* (Musician 2).

Evolving the Programme Model: The STROKESTRA programme evolved from the pilot term to the SCP in terms 5 and 6, the main adaptation being the involvement of **community volunteers** rather than NHS clinicians in the later stages. Nevertheless, the **overarching goal remained the same**, that is to improve the **quality of life** for stroke survivors and their families, as well as the broader structure of the sessions. The Project Leader and Primary Volunteer assumed **responsibilities** for recruitment and logistics in the SCP (previously this was undertaken by clinicians). There was **less emphasis on the individual goals/physical needs** of stroke survivors in the SCP and **greater emphasis on creating a band-feel** in the groups: “...slightly different because [...] we weren't working with the rehab team, our goals were [...] more exclusively focused on the... the music making and [...] working a bit more on the feeling of being a band and putting a show together” (Workshop Leader).

4.1.3 Challenges (Implementing)

Four challenges were identified in relation to the implementation of the SCP:

1. **Competition (for RPO musicians).** The SCP was perceived to be highly competitive for RPO musicians to get on board. This exposed a tension between “more” versus “less” STROKESTRA-experienced musicians. According to one musician, a core group of “more experienced” members tended to be favoured for certain opportunities, creating an imbalance with those who would have liked to contribute, but who were not involved during the initial terms.
2. **Recruitment (survivors/carers).** Recruitment to the SCP was difficult: a number of people did not wish to join because they typically thought “it’s not for me” and there was an **assumption** that doing something with **Classical music was “highbrow”**, so beyond their comfort zone: “I wonder[ed] what this is going to be like, with it being the Royal Philharmonic Orchestra...I thought oh blimey! You know that’s a bit...highbrow” (Carer 1).
3. **Logistics.** Various logistical issues arose in delivering the programme:
 - **Venues:** there were unexpected problems with acoustics and temperatures in some venues;
 - **Timings (facilitators):** RPO musicians had very early journey starts because workshops had to fit around professional performances. Likewise, the workshop dates were not always ideal for volunteers if they occurred during holidays, which impacted their participation.
 - **Absences (survivors/carers):** people sometimes felt unwell on the day, affecting attendance.
4. **Funding:** it was acknowledged by the Project Leader that the SCP is expensive to run: “the term cost basically like [x] grand” (Project Leader).



4.2 Experiencing the SCP

4.2.1 Group Dynamic

Stroke survivors and carers described the group dynamic in the workshops as **caring**, **supportive** and **sensitive**: *"I've not met a group of people so friendly, so caring...so patient"* (Stroke Survivor 6). Facilitators described the SCP workshops as **creative**, **musically satisfying**, **relaxed**, **fun** and **positive**, and they actively worked to create a comfortable and supportive group dynamic. In particular, the SCP workshop was considered to be a **safe space** where people could **trust** each other: *"in case I have a fit... but I know...when I'm there they can look after me [...] they make everything happy"* (Stroke Survivor 4). According to the facilitators, building rapport with stroke survivors and carers was central to the SCP. **"Banter"** served as an opportunity to normalise situations through sensitive and careful joking and humour: *"I [make fun] of all the musicians and the staff...just as much as myself and also...participants as well, which I think...creates such a kind of like a levelling, normalised...kind of thing"* (Workshop Leader).



4.2.2 Musical Interactions

The main purpose of the workshops was to enable people to experience musical interactions. Throughout the sessions, musical interactions led to feelings of equality: *"one person couldn't prevail without the other"* (Music Student 2). The idea of **"being in sync"** (Music Student 3) contributed importantly to the cohesion of the group. Likewise, playing the same instrument encouraged a **"band feel"**: *"if people are playing the same instruments to each other, say sometimes we'll say 'oh okay you three you'll be playing the tambourine'...and then automatically they've got this little thing going and suddenly you're like in little bands together, you know is quite cool!"* (Musician 2). Collective singing helped with group bonding: *"Like singing has...something different that's bonding the group together. I felt more unified with the group because...we were singing the same thing"* (Music Student 1).

4.2.3 Performance

Preparation: The idea of giving a public performance was gradually introduced to stroke survivors across the term, allowing them plenty of time to familiarise themselves with the idea. Facilitators supported the preparation of the performance by **explaining** and **reinforcing** the way it was going to go, including providing relevant logistical details and **reassuring** participants to avoid any surprises or last-minute worries; holding **extra sessions** on the two consecutive days before the performance (therefore meeting three days in a row at the end of each term); **replicating** in the performance the seating plan from the workshop sessions to maintain familiarity of sitting next to a certain instrument or hearing similar sounds; **focusing** on the performance pieces in the workshops leading up to it, thereby building participants' confidence on them; and ensuring **enough RPO musicians** would be present in the performance to bring the ensemble back together should unexpected deviations occur.

Achievement: The performance was regarded as a significant finale to the SCP, for it allowed participants the opportunity to share their achievements with friends and relatives: *“most of the people want people to see what they’ve been up to because they’re proud of it”* (Project Leader). Participants reported many **positive** experiences, including **performance highs** (*“we haven’t stopped talking about that!”* (Stroke Survivor 1)), **sense of achievement** (*“some were looking forward to it and I have to say afterwards they were absolutely on a high because it had gone very well”* (Primary Volunteer)); feeling **surprised** (*“I surprised myself. I think, yes. You know that I could do it and...sitting in public and do it. That was the biggest surprise!”* (Stroke Survivor 11)); **experiencing flow** (*“I was concentrating [...] the audience disappeared”* (Stroke Survivor 11)); having a special experience or **cathartic energy**; and creating **positive memories** (*“I’ve got the links from the CDs and stuff like that. So every so often I put it on”*. (Stroke Survivor 12)).

4.2.4 What People Gain

Hopes: When first joining the SCP, some participants were not sure what to expect from the programme, while others reported a range of hopes. Some hopes were about **wanting to participate** (*“Just literally being involved”* (Stroke Survivor 1); *“see what it’s like”* (Stroke Survivor 4)), some were about **learning a new instrument or about music**; some related to social aspects, including getting more comfortable and relaxed in other people’s company and getting out of the house, while others simply wanted to **enjoy** the activity. Interestingly, for carers, they wanted their partner or the stroke survivor to be involved so as to help keep their **mind active**. Examples of how particular hopes were fulfilled for some stroke survivors were evident for those who completed pre- and post-term interviews (see Table 8).

PARTICIPANT HOPE	PRE-TERM	POST-TERM
Stroke Survivor 2: playing again	<i>“I’m hoping to try and progress on playing my guitar”</i> .	<i>“When I...started there, I thought...I want to try and learn...the guitar. And a week later I went out and bought one. Now...I can actually play”</i> .
Stroke Survivor 11: social confidence	<i>“To relax in other people’s company”</i> .	<i>“It was just that initial couple of times that you go and that you don’t know anybody, and you don’t know what’s going to happen...but then...as I say, counted down the days to get there! It was that good”</i> . [laughs]
Stroke Survivor 12: playing again	<i>“I already feel better about getting back into me music...now it sparked an interest in music”</i> .	<i>“Since [stroke] I’ve not really picked the guitar up. So, but I wanted to see if I could get back into it and of course STROKESTRA was ideal”</i> .

Table 8. Examples of hopes from stroke survivors (pre and post-term interviews)



Benefits: stroke survivors and carers reported a range of benefits from attending SCP sessions. For stroke survivors, ten broad categories of benefit emerged:

1

Achievement and Purpose.

"Sometimes, I'm waiting for the next request [task] to see if I can deal with that! [...] it's a boost for me" (Stroke Survivor 10)

"If you have a stroke your life just stops. But with this, it gives you something back" (Stroke Survivor 1)

2

Cognitive Benefits

"It's helped me immensely because it's making my brain work" (Stroke Survivor 10)

3

Confidence

"I feel a lot happier amongst people now. I don't feel quite so...isolated and...a fool, if I can't quite keep up or I have to think a little bit longer" (Stroke Survivor 11).

"One of the [survivors] said..."since I had me stroke I haven't been anywhere or [done] anything [...] I just booked tickets to go to rugby...to an away game...I haven't been [to] that for absolutely ages" (Primary Volunteer).

4

Emotional Benefits

"It took...the depressive thoughts and things away, or push them to one side. And it really just showed that...you can enjoy yourself" (Stroke Survivor 12).

5

Enjoyment

"The [stroke survivor] who still [...] decides to bang the cymbal every time that they hear a...double entendre or something! You know 'weheyy!' [laughs]" (Musician 8)

"Just passes too quick" (Stroke Survivor 4).

6

Gaining Independence

"I felt going to Strokestra and being able to drive there, I was getting a little bit of me own life back" (Stroke Survivor 12).

7

Interest

"I didn't expect it to be as interesting" (Carer 1).

"I've got nothing to look forward to and now I have!" (Stroke Survivor 1).

8

Musical Gains

"I've never played an instrument in me life [...] but...once I got into this, I really enjoyed it!" (Stroke Survivor 4).

"[Stroke survivor name] had never picked up a trombone before and now he's teaching the guy that picked it up a bit later than him" (Musician 9).

9

Physical Benefits

"Before I found it difficult to grip, so...I practised every day gripping so that when...we did...Strokestra I could do it better!" (Stroke Survivor 11).

10

Social Benefits (including peer support)

"We're all on the same boat" (Stroke Survivor 1)

"It [...] helped me to actually be around people because...I got to a point where I just closed myself off in the world". (Stroke Survivor 2)

"You was made welcome...as soon as you went in" (Carer 4).

Three of these categories emerged in all of the stroke survivors' interviews – **Social Benefits**; **Musical Gains** and **Enjoyment**– with these being the most frequently reported responses. A visual summary of the proportions of items coded for the ten benefits across all of the participants' data, including stroke survivors, carers and facilitators, is given in Figure 3 (proportions remained similar when applied to stroke survivors' interviews only).

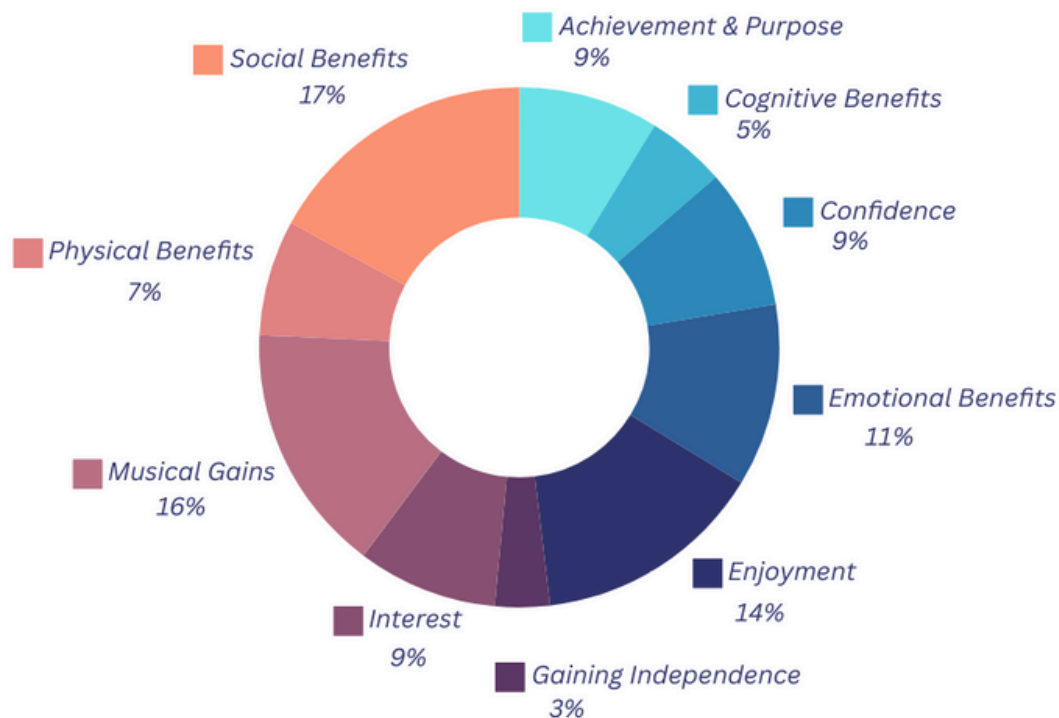


Figure 3. Proportions of items coded for stroke survivors' benefits (from all participants).

4.2.5 Challenges (Experiencing)

In general, there were seven main challenges identified:

- 1. Self-esteem (musically-experienced stroke survivors).** Problems with self-esteem emerged for stroke survivors who had prior musical experiences before their stroke: *"I think we really underestimated how stressful that is for them because obviously they can tell if, if they're not doing it right, [...] their kind of identity being challenged"* (Project Leader).
- 2. Initial Nervousness (survivors/carers).** Participants experienced initial anxiety about doing the SCP workshops: *"Very nerve wracking. A bit frightening, because I didn't know what to expect and I didn't know any of these people. And...I hadn't been in a crowd as such for a long time...now, Thursday can't come quick enough"* (Stroke Survivor 11). In addition, some of the participants felt butterflies ahead of the performance: *"just that kind of personality of people...she basically had been up since seven because she couldn't sleep cos she would have butterflies"* (Project Leader).
- 3. Frustration (survivors).** It was evident that some survivors experienced considerable frustration about not being able to achieve certain tasks during the SCP: *"I would have liked to be able to have done more myself, you know what I mean. But once I sort of realised that there is a limit, then I was happy"* (Stroke Survivor 11).
- 4. Worry about overdoing it (survivors).** Secondary anxiety was caused because stroke survivors were worried that they were doing too much in the SCP: *"the only thing that did worry me was how I felt after the concert, you know for the next three days"* (Stroke Survivor 6).
- 5. Fatigue (survivors).** Some of the participants experienced considerable tiredness from participating in the SCP: *"I felt like death warmed up for the next two/three days! [...] because I've got so into it"* (Stroke Survivor 6).
- 6. Fear of being judged (survivors).** Some participants were afraid of being judged, especially in the performance: *"I was excited cos I was looking forward to it; but I was very nervous about sitting there and people seeing me...and judging"* (Stroke Survivor 11).
- 7. Concern about the SCP ending (survivors/carers):** Participants were concerned about what they would do and how they would feel after the SCP ended: *"we'll miss it when it stops. That's the problem...and that's when depression starts"* (Stroke Survivor 1).

4.3 Facilitating the SCP

4.3.1 Relationships



Relationships between facilitators, stroke survivors and carers were established via **collaboration** in the SCP workshops. Collaboration led to group **bonding** and this was achieved in different ways:

1. Taking time with each other: *“everyone who was there was absolutely great...especially the musicians like...took the time to listen and teach” (Stroke Survivor 2).*

2. Developing a friendly atmosphere was central to the bonding of people within the group: *“...they remember you and you remember them. So you're building a bit more on that relationship. So the first time you're getting to know people and their capabilities. So this time [...] you are being treated like an old friend.” (Musician 8).*

3. Creating a caring dynamic: *“caring and quite sensitive to people's needs” (Musician 2).*

4. Having conversations: *“just literally sitting down and having a conversation with somebody...it just builds up a relationship” (Musician 4).*

5. Building trust: *“you have to work with a flow...and a response. And that does only come from experience, plus a...kind of trust in your own skills and the skills of the musicians, and...of the people that are in the room as well” (Workshop Leader).*

6. Working on the same level: *“it's not like...patient and doctor. It's a lot of one on one, side to side” (Music Student 2).* This was also achieved through having a sense of **humour** and via **banter**.

7. Providing mutual support: *“We were helping each other though, because sometimes I would forget” (Music Student 4).*

8. Welcoming each other: *“[Primary Facilitator] as soon as I walked in the door...big smile, greeted me, really friendly; [...] she put me at ease” (Stroke Survivor 12).*

4.3.2 Roles & Tasks

Facilitators developed **varying roles** and executed **numerous tasks** in running the SCP sessions as stated below. All of the facilitators had to **monitor and respond to the people in the room** as well as **manage social aspects** of the delivery of the SCP.

- **Project Leader:** the main point of contact for the SCP; responsible for logistics, practicalities, recruitment, health and safety; understanding participants' needs; trainings and briefings.
- **Workshop Leader:** led artistic elements of the SCP, including directing workshops and performances as well as trainings and briefings.
- **RPO musicians/music student volunteers:** provided artistic and practical music support.
- **Primary Volunteer:** supported recruitment; responsible for logistics, health and safety; understanding participants' needs; facilitating involvement.
- **Volunteers:** responsible for logistics; health and safety; facilitating involvement.

4.3.3 Challenges (Facilitating)

There were two main challenges identified in facilitating the SCP:

1. **Managing unanticipated situations.** Some of the musicians and leaders indicated that they had to manage unanticipated situations whilst facilitating the SCP and that this could be challenging. For instance, it could be difficult to know what to do if people were struggling: *"It's quite hard to see...we've had a few times where people [were] really struggling or get upset or they need to leave the room"* (Musician 2). Likewise, there were times when they did not notice if or when someone needed to take a break: *"one guy...was standing up and playing on the marimba for ages desperately trying to work out his [rhythm]...and then he started going a bit wobbly and you realised that...it hasn't occurred to him or to me that he's been standing up for 40 minutes [and] he...needs to sit down!"* (Musician 8). Similarly, even though facilitators knew it was important to monitor fatigue among stroke survivors and carers, they did not always remember to do so: *"we got a bit too relaxed with the whole thing and [were] forgetting actually how vulnerable a lot of the people are"* (Workshop Leader).
2. **Working outside of one's comfort zone.** The musicians sometimes found the session activities challenging because they were outside of their comfort zone, such as the need to improvise: *"how on earth am I gonna prepare for this"* (Musician 5).



5. CONCLUSIONS

5.1 Summary of Findings

The research data provided nuanced and detailed insight into the SCP, specifically how it was implemented, experienced and facilitated. Responses to the research questions are given below.

Research Question 1: How was the SCP implemented?

The setting-up of the SCP involved **training** facilitators, **recruiting** participants (stroke survivors and carers), **managing logistics** and **practicalities**, including sorting out venues, supplying name badges, ear defenders, instruments and refreshments, as well as booking taxis. These tasks were undertaken by the Project Leader with recruitment supported by the Primary Volunteer. SCP workshops followed a **consistent structure** (2-hours with a break midway) and involved a **set of music activities** directed by the Workshop Leader. The workshops involved **briefings**, while the programme itself **evolved** over several terms to run with community volunteers instead of NHS clinicians.

Research Question 2a: What recruitment strategies were used?

The Project Leader was responsible for recruitment to the programme, which involved **distribution** of promotional materials and **contact** with local stroke organisations and associations. The recruitment process relied upon the Primary Volunteer who **assisted** by making direct contact with stroke survivors and carers established through their work in healthcare settings.

Research Question 2b: What training strategies were used?

Formal training sessions for RPO musicians and University music students were provided by the Workshop Leader. Facilitators indicated that training was also gained via **experience** of participating in the SCP as well as through ad hoc **conversations** with each other. Briefings and self-reflection contributed to training. In this case, all of the volunteers already had prior experiences in working with stroke survivors.

Research Question 2c: What logistical strategies were used?

The **choice of venue** for the workshops was found to impact importantly upon accessibility to the SCP and served to break down social barriers through reaching people from different communities in the Hull region. Other considerations about places and spaces were noted, including: choosing somewhere **familiar** to people, **room size**, **temperature**, **lighting**, **ventilation**, **kitchen facilities**, **seating equipment**, **accessibility** and **disabled toilet facilities**, and the need for a balance between geographic location and other important aspects – critically **acoustics** – was noted.

Research Question 3: What were the experiences of stroke survivors and carers participating in the SCP?

The stroke survivors and carers experienced a strongly **positive group dynamic** in the SCP, which was described as **trusting, caring, supportive** and **sensitive**. Musical interactions led to a “**band feel**” and people indicated that they liked the feeling of “**being in sync**” with each other. The performances were carefully supported and provided a sense of **achievement**. People articulated a range of **hopes** and **benefits** from participation in the SCP, especially **social benefits, musical gains** and **enjoyment**. Overall, the research participants (both stroke survivors and carers) were extremely positive about their experiences of participating in the programme.

Research Question 4: What were the experiences of people facilitating the SCP?

Musicians and volunteers revealed their motivations for facilitating the SCP and, in so doing, articulated some of their experiences, including finding the programme **liberating, enjoyable** and **interesting**. They described the workshops as **creative, musically satisfying, relaxed, fun** and **positive**. The RPO musicians also explained that they liked the way that the SCP created **variety** from their regular work.

Research Question 5: How did leaders, musicians and volunteers support stroke survivors and carers in the SCP?

The facilitators **collaborated** with stroke survivors and carers to ensure group **bonding** and a positive, friendly dynamic. This was achieved via **taking time** with each other, **developing friendships**, being **caring and sensitive**, having **conversations, building trust**, providing **mutual support**, being **welcoming** towards one another and making people feel like they are **working on the same level**. “**Banter**” and humour was especially important in achieving the latter. The facilitators assumed different roles and responsibilities, specifically recruitment and understanding participants’ needs (Project Leader/Primary Volunteer), logistics, health and safety (Project Leader/Primary Volunteer, other Volunteers), artistic leadership (Workshop Leader), and artistic or music support (RPO musicians, music students). All of the facilitators had to learn to “**read the room**” and **manage social aspects**. Specific strategies were used by the facilitators to prepare the stroke survivors and carers for the public performance, including **explaining, reinforcing** and **reassuring** them about what was going to happen, holding **extra sessions, replicating** set ups, **focusing** on pieces and **providing** enough RPO musicians to support them.

5.2 Challenges & Recommendations

A number of challenges were identified in relation to implementing, experiencing and facilitating the SCP, which are summarised below. In relation to these points, recommendations or suggestions are put forward for future consideration:

1. CHALLENGE: The SCP is highly **competitive** for RPO musicians to get onto, which has created tensions among the orchestral players about those who are “more” or “less” experienced.

RECOMMENDATION: If appropriate, provide a formal rota to enable new and experienced musicians to be involved in SCP opportunities, thereby increasing the pool of facilitators for the SCP.

2. CHALLENGE: **Recruitment** to the SCP is difficult, as some stroke survivors and carers think “it’s not for me” or assume that it will not suit them because Classical music is “highbrow”. It was noted that some ways of reaching out to potential participants were less successful than others, such as through stroke groups. Further work is needed to identify additional approaches to recruitment, which help overcome individuals’ assumptions that “this is not for me” or that the programme will be too rarefied.

RECOMMENDATION: Provide blogs and clips from former participants to encourage people to try it out, offer “taster” sessions, and emphasise that the programme does not focus solely on classical music. Develop relationships with social prescribers, regional clinicians and GPs to improve recruitment reach and build promotion via team effort to target hospital wards, stroke charities and clinics. Consider opening up the programme to other members of the community, extending or adapting the provision to enable it to support people with other healthcare conditions.

3. CHALLENGE: there are a number of **logistical** challenges in implementing the programme, including choosing suitable venues, finding dates and times that will maximise participation and working with absences from stroke survivors and carers due to illnesses.

RECOMMENDATION: build up a portfolio of venue options and monitor patterns of attendance so as to identify peak times for participation.

4. CHALLENGE: The programme is **expensive** to run, so funding it is challenging.

RECOMMENDATION: Work with local creative practitioners, musicians, Music Hubs and volunteers, including university music, health and social care students, to help them start up in-house community versions of the project (for example, The Sensational Stroke Ensemble in Hull, UK) by supporting their initiatives and helping them to source local funding.

5. CHALLENGE: Stroke survivors and carers might experience **negative emotions** during the SCP, such as problems with self-esteem, nervousness, frustration at not being able to do things, worry about overdoing things, fatigue, fear of being judged (in the performance) and concerns over what will happen when the SCP ends.

RECOMMENDATION: Provide guidance for stroke survivors and carers about the range of emotions that might be experienced during the SCP, including both positive and negative, to help them manage expectations about their participation. Provide training to facilitators about what to do in these situations, such as offering stroke survivors/carers a break, spending one-to-one time with them, noticing the signs, and working with carers to support survivors. To address the problem of what to do when the SCP ends, see recommendation 4.

6. CHALLENGE: Facilitators may find that it is difficult to manage **unanticipated situations** during the SCP. Additionally, they may experience difficulties because of the need to work **outside of their comfort zone**.

RECOMMENDATION: Continue to provide training and experience for musicians to assist them with managing the delivery of the SCP and encourage their self-reflections. Volunteers without prior experience in working with stroke survivors should be trained and briefed with other facilitators.

5.3 Areas of Good Practice

The research team considers the SCP to be an effective music-therapeutic programme because of the reported range of positive experiences for stroke survivors, carers and facilitators alike (see Figure 4).

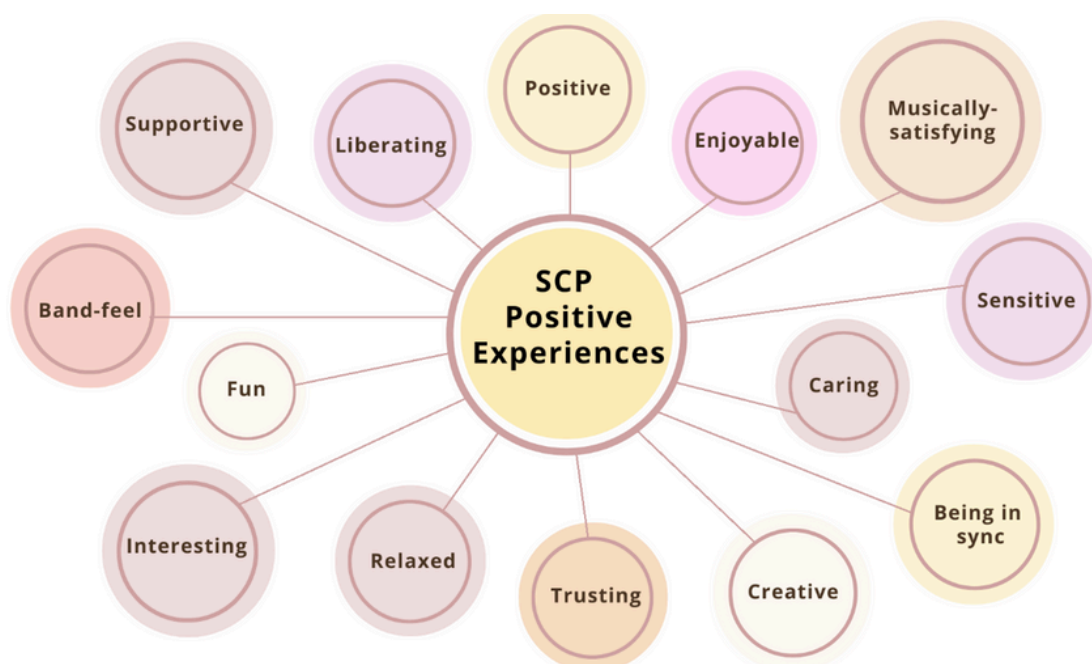


Figure 4. Range of positive experiences for people involved in the SCP

The research team identifies the following areas of good practice in the SCP:

- Developing a nucleus pairing of Project Leader and Primary Volunteer to maximise recruitment;
- Provision of training for facilitators via formal sessions and experience;
- Provision of briefings and de-briefings with facilitators to provide regular information and reflection;
- Willingness to evolve the STROKESTRA programme based on changing circumstances and the needs of individuals or the group;
- Ensuring a consistent workshop format and content so people come to know what to expect, although allowing for flexibility as appropriate;
- Creating a positive group dynamic through collaboration and bonding with emphasis on a “band feel” and “being in sync” as well as an approach which recognises the social importance of attendance for many;
- Preparing stroke survivors and carers for public performance by explaining, reinforcing, reassuring and replicating what will happen in workshops whilst retaining a relaxed pressure-free environment where mistakes don’t matter;
- Effectively working out roles and tasks for leaders, musicians and volunteers.

The above findings and recommendations will feed into the development of an online resource about setting up, delivering and supporting arts-based therapeutic programmes in community settings (for further information, see King et al., forthcoming).

5.4 Acknowledgements and Further Information

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