

STROKESTRA

Stroke Rehabilitation through Creative Music-Making

Pilot Programme Report



Royal Philharmonic Orchestra



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Executive Summary

STROKESTRA is a pioneering collaboration between the Hull City Council Health & Wellbeing Board, the Royal Philharmonic Orchestra (RPO) and Hull Integrated Community Stroke Service (HICSS) which uses group creative music-making alongside professional musicians to drive patient-led stroke recovery in stroke survivors and their carers.

Beginning in December 2014 with an intensive Research & Development phase which brought together professional musicians and stroke therapists to devise appropriate musical techniques for use with stroke patients, a pilot programme involving a series of intensive projects took place in 2015. The pilot was designed to test the intrinsic value of these specially-designed creative music workshops for a wide range of stroke rehabilitation needs including improved sensation, mobility, strength, flexibility, cognitive function, socialisation, communication, wellbeing and more. Patients and carers were referred by HICSS therapists and consented to take part in the project. All patients worked with their referring therapist to create a list of individualised goals to work towards during the project, ranging from social and communication goals to improved mobility, wellbeing, speech and language.

From May to October 2015, a total of 50 patients and carers took part in 16 days of intensive project work during which they tried out instruments, listened to music, conducted musicians, improvised and created music alongside specially-trained world-class professional musicians, all supporting their work towards their stroke recovery goals.

The pilot programme culminated in a high-profile performance outcome ahead of the RPO's season opening concert at Hull City Hall on 1st October 2015 featuring stroke survivors, carers, therapists and RPO musicians performing original pieces of music in a celebratory showcase of their creative and rehabilitative successes with family, friends, guests and the wider public.



Figure 1 STROKESTRA performs at Hull City Hall.

Throughout the project, therapists and staff carried out a robust service evaluation utilising a variety of qualitative and quantitative data to evaluate changes in patients' social, physical, functional, cognitive, communicative and psychological domains. Patients, carers and staff reported marked improvements in a number of areas:

- 86% of patients felt the sessions relieved disability symptoms citing improved sleeping, reduced anxiety, fewer dizzy spells and reduced epilepsy symptoms.
- 91% of patients reported social benefits, including improved relationships and communication skills.
- 86% of patients indicated that the project provided cognitive benefits, including reports of increased concentration, focus and memory.
- 86% of patients felt the project provided emotional benefits, citing increases in confidence, morale and a renewed sense of self.
- 71% of patients achieved physical improvements, including improved walking, standing, upper arm strength and increased stamina.
- 56.3% of patients achieved at least a 10 point improvement on the hand use section of the Stroke Impact Scale, while a further 33.3% achieved this result in the physical strength section.
- 100% of carers reported improvements in wellbeing, including respite from their role as a carer and improved relationships with their relative after participating alongside them.

'I feel I am walking so much better and want to do more now. I am also sleeping better which I feel is from relaxing [through] me playing the music.'

– Patient

'It was the first time he was motivated, it was the first time he had socialised and it was the first time he wanted to do something after - we went out for tea. I think he put his embarrassment to one side. It was the first time I saw him smile in 3 months!'

– Carer

The evaluation also highlighted opportunities for improvement and growth in long-term future programmes, including: increased opportunities for speech and language therapy through the use of small group work, development of patient-led recruitment tools to reassure prospective patients, the expansion of musical activity to inpatients to assist the transition from rehabilitation units to home, and the integration of students from the University of Hull to support the development of local expertise and regular interim delivery.

1. Introduction and Background

1.1 Stroke introduction

Stroke is a life-threatening medical condition that occurs when the blood supply to part of the brain is cut off either due to a blood clot (an ischaemic attack) or a burst blood vessel in the brain (haemorrhagic stroke). Every year, more than 110,000 people have a stroke in England. Risk factors include smoking, being overweight, lack of exercise, high cholesterol, atrial fibrillation (irregular heartbeat) and diabetes (NHS, 2009).

There are over 1.2 million stroke survivors in the UK (Health and Social Care Information Centre, 2015), with half of stroke survivors suffering stroke-related disabilities (Adamson, Beswick and Ebrahim, 2004) and over a third requiring help to complete activities of daily living (Royal College of Physicians, 2015).

Stroke can cause a wide range of disabilities in patients including motor control difficulties, sensory disturbances, communication difficulties including aphasia, problems with thinking and memory and emotional distress (NIH, 2014). One third of stroke survivors experience post-stroke depression (Hackett, Yapa, Parag & Anderson, 2005) and 73% of survivors lack confidence (Stroke Association, 2013).

The total economic cost of strokes in the UK amounts to around £9 billion a year (Saka, McGuire & Wolfe, 2009), taking into account frontline health and social care costs, informal care costs, productivity losses and benefit payments due to stroke survivors.

1.2 Theoretical background for the programme

There has been growing evidence in the field of stroke and neurological rehabilitation that music used in a variety of therapeutic ways can result in improved outcomes. The use of the word music therapy and therapeutic music are used interchangeably in the literature and different studies have employed different meanings for the terms (Raglio et al., 2013).

1.2.1 The effect of music interventions on neural networks

Särkämö et al. (2008) concluded that music listening activates a bilateral network of brain regions related to attention, semantic processing, memory, motor function and emotional processing and can enhance recovery by encouraging verbal memory and focused attention as well as music reducing low mood and signs of confusion. Fukui and Toyoshima (2008) suggested music listening may facilitate neurogenesis, regeneration and repair of cerebral nerves by influencing the secretion of hormones leading to cerebral plasticity. Their work promoted music as a non-invasive therapy which may contribute to preventing forms of Alzheimer's and dementia.

Other studies have focused on music as an auditory stimulus which can increase blood flow to stroke affected areas (Antić, 2008), promote relaxation, improve mood, and support physical and mental activation (Forsblom et al., 2009). Music listening may enhance grey matter changes and neuroplasticity, providing a stimulus to temporal, frontal, parietal, cerebellar and subcortical areas as all are involved in auditory, cognitive, motor and emotional processing (Grau-Sánchez et al., 2013; Särkämö et al., 2014). These changes in neuroplasticity have shown it is still possible to make improvements years after a stroke (Wolf et al., 2008).

1.2.2 The effect of music interventions on motor functions and gait

A Cochrane review (Bradt et al., 2010) concluded that rhythmic auditory stimulation can be beneficial for improving gait parameters in stroke patients, including gait velocity, cadence, stride length and gait symmetry.

The review included randomized control trials, parallel group designs and cross-over trials with people aged 16 and over and where music was delivered by a trained music therapist or by trainees in a formal music therapy programme. However, many studies which do not meet this criteria have concluded that music, when used therapeutically but not delivered by a qualified music therapist, can still be beneficial to recovery following stroke.

Schneider et al. (2007, 2010) found that music supported training can be more efficient than functional motor training alone. They concluded that motivational and emotional factors evident in music training but not standard motor training may have contributed to the improved motor outcomes.

Thaut and McKintosh (2014) refer to neurologic music therapy (NMT) which has been established as a new model of music therapy within medicine. Evidenced-based clinical interventions use motor, speech and language and cognitive training which can be cued by auditory rhythms. These auditory cues directly affect the brain development and functioning by providing auditory feedback around a patient's anticipation, control and timing of movements or speech.

Rhythm focused studies have supported the use of music to promote upper limb recovery following stroke. Altenmüller et al. (2009) illustrated improved fine and gross motor movements in the upper limbs. Other therapy work has shown that music adds social meaning to the typical high intensity repetitions promoted in physiotherapy to improve upper limb function. This action supports self-management and compliance with physiotherapy (Van Wijck et al., 2012).

1.2.3 The effect of music interventions on cognition

Särkämö et al. (2012) found that listening to pleasant music can have short term effects on visual awareness in patients with visual neglect, associated with functional coupling between emotional and attentional neural regions. This concept has been supported by further studies (Rodriguez-Fornells et al., 2012). Särkämö et al. (2012) also concluded that daily music listening can improve auditory and verbal memory, focused attention and mood and induce grey matter changes in the early post stroke phase. More recent studies also support the concept that listening to classical music can promote visual attention and help reduce unilateral neglect (Chen, Tsai, Huang & Lin, 2013; Tsai et al., 2013). Other studies have indicated that neuroplastic changes can be induced in chronic stroke patients (Amengual et al., 2013; Jamali, Fujioka, & Ross, 2014).

Another study (Thaut et al., 2009) concluded that engagement in four 30-minute sessions of music therapy involving interactive musical group improvisations with highly focused functional and attention content and task structure relevant to individual clinical rehabilitation goals indicated improved executive and emotional adjustment.

1.2.4 The effect of music interventions on speech and language

There is growing evidence for the use of music in the treatment of neurologically based language and speech disorders (Hurkmans et al., 2012; Lim et al., 2013). Although methodological quality was reported to be poor, findings indicated that there are potential benefits of melodic intonation therapy; this therapy involves speaking with a simplified and exaggerated prosody characterised by a melodic component (two notes high and low) and rhythmic component (two durations long and short) involving the repetition of phrases set to musical structures. The approach aims to exploit intact communication centres in the right hemisphere but other studies have reported it also reactivates left prefrontal structures implicated in complex cognitive and social behaviours (Belin et al., 1996; Breier et al., 2010).

1.2.5 The effect of music interventions on mood and wellbeing

The effects of music on mood and wellbeing are well documented. Josephsson and Lindquist (2014) conducted a study to explore the experiences and effects of 17 patients who have experienced stroke. Their work showed that rhythm and movement therapy increased patients' body awareness, energy, positivity, and contributed to a sense of achievement whilst supporting more positive adjustment following stroke.

Music therapy has been shown to promote social interaction and positive mood, as well as lower depression and anxiety, in stroke patients (Nayak, Wheeler, Shiflett & Agostinelli, 2000; Wheeler, Shiflett & Nayak, 2003; Forsblom, Laitinen, Särkämö & Tervaniemi, 2009; Guetin et al., 2008; Kim et al., 2011; Poćwierz-Marciniak, 2014).

Of particular relevance due to its format, a group creative music intervention undertaken in a small group of non-stroke elderly patients at Blacon Community Trust outlined the benefits of music sessions in which residents composed individual pieces of music interactively with musicians from Manchester Camerata, contributing to a sense of wellbeing through control over musical material, opportunities for creativity and identity making, validation of life experience and social engagement with other residents and musicians (Habron et al., 2013).

2. Programme Structure

2.1 Development of the programme

The Royal Philharmonic Orchestra (RPO) began a five-year concert residency at Hull City Hall in autumn 2014. As part of the residency, the Orchestra collaborated with Hull City Council to develop community outreach programmes that would use the Orchestra's award winning Community & Education department as a resource to respond to local need. Through meetings with the Health & Wellbeing Board, the city's Public Health department agreed to fund a pilot programme exploring the possibilities of using group creative music-making alongside world-class professionals to aid stroke recovery. The Public Health team brought in Hull Integrated Community Stroke Service (HICSS), a specialist stroke service and part of the Humber NHS Trust, to take the role of clinical partner in the planning and delivery of the programme.



Figure 2 Participants meet Workshop Leader Tim Steiner on the first day of STROKESTRA.

2.1.1. About the partners

Hull Integrated Community Stroke Service (HICSS) is a dedicated health and social care team that supports stroke survivors in Hull. Funded by the Hull Clinical Commissioning Group as part of the Humber NHS Trust, HICSS uses a team of occupational, physical and speech therapists, nurses and clinical psychologists to provide appropriate support including inpatient care, Early Supported Discharge and longer term community rehabilitation to stroke survivors across Hull.

The **Royal Philharmonic Orchestra (RPO)** was founded in 1946 with the aim of bringing world-class music to communities around the UK and abroad. In addition to delivering more than 170 mainstream concerts per year, RPO Resound, the Orchestra's community and education programme, uses the transformative power of music to reach the communities the Orchestra serves, providing inspiring musical experiences in a range of settings from prisons to primary schools and beyond. Each project is bespoke and delivered in collaboration with our partners to meet the needs of specific participant groups and achieve artistic, social and personal aims, including improving participants' aspirations, abilities and life chances. With over 23 years' experience delivering innovative community and education projects, RPO Resound works to gain a wider impact through music outside the traditional concert hall format.



Figure 3 Members of the Royal Philharmonic Orchestra

2.2 Structure

The initial stage of the programme featured the RPO and HICSS teams researching existing literature around music and stroke rehabilitation to understand the evidence base for its use in addressing various areas of stroke recovery. The HICSS team also undertook explorations with their research team to understand the feasibility for formal research around the programme.

Following this initial review of the literature, an extensive research and development phase brought together multi-disciplinary stroke experts from HICSS, a team of 6 specially trained Royal Philharmonic Orchestra musicians and RPO Workshop Leader Dr Tim Steiner for practical explorations of the possibilities of the collaboration. Through hands-on workshops featuring instruments and creative music-making, the team developed musical techniques with intrinsic value for stroke rehabilitation. Workshops also included brainstorming discussions about the ideal structure of patient sessions including length, time of day, number of patients, patient progression and maximising use of the orchestral musicians.

A three-month planning period followed which included the development of a series of intensive projects throughout spring and summer 2015 to trial the techniques devised during the development phase. All logistical details including dates, times, venues, transportation and catering were organised and HICSS staff began recruiting participants through therapist referral. Staff completed patient base-line assessments and gathered patient records, and patients were asked to determine individual goals to work towards during the project, including social, cognitive, functional, communicative, physical and psychological goals.

Five months of intensive fortnightly projects followed which involved 2-day projects led by the RPO musician team alternate with 1-day interim projects led by HICSS staff trained in musical leadership by the RPO team. Two participant groups, a morning and an afternoon group, attended two-hour sessions on each project day. Sessions included social aspects such as communicating during tea breaks and through musical activities, as well as the specially designed musical techniques that aimed to contribute to various stroke rehabilitation needs.

Group music-making techniques were adapted to facilitate rehabilitation work and chosen and led by the Workshop Leader. Example techniques include:

- **Conducting musician improvisations** – RPO musicians improvise while following cues from participant conductors. Patients work on motor planning and fine/gross upper limb coordination and movement as they move arms up and down to indicate higher or lower notes and open and close hands to signify dynamics; abstract thinking to understand the relationship between their movements and the resulting music; and attention to the group process in order to pass the conducting role on to other participants. Patients may choose to conduct standing or sitting, and the exercise empowers patients with limited independence by offering complete control over the music created by a professional musician.
- **Copying of drum patterns** – Participants copy drum patterns demonstrated by the Workshop Leader. This exercise requires patients to understand spoken instructions and visual cues, and successfully involve fine and gross upper limb movement, coordination, timing, motor planning, initiating, inhibiting and sequencing movement. This technique also supports the development of a feeling of belonging, as all patients contribute to a group sound while receiving immediate auditory feedback about the accuracy of their movements through drum sounds.

- **Groove work** - Participants and musicians simultaneously repeat short, improvised phrases, while the Workshop Leader picks out complementary riffs and directs players to start, stop and play together in duets, trios or small groups. This exercise quickly creates high quality artistic outcomes while requiring patients to use various physical skills depending on their chosen instrument, as well as maintain attention to spoken and symbolised instructions, initiate and inhibit movement as directed, practice auditory attention to locate similar or complementary riffs and exhibit creativity to create a unique phrase.
- **Musical ‘postcard’ creation** – Participants, staff and musicians work in small groups to create short musical sections representing a chosen theme or image. This technique requires verbal and musical communication, abstract thinking, holding and playing of instruments and creativity, as well as supports socialisation through sharing ideas and creating something new with others.

Instruments were identified for their potential rehabilitative uses and patients wishing to work on relevant goals were supported to access appropriate instruments throughout all activities. For example, tubular bells require standing to play and so are given to patients wishing to work on this goal while ‘wah-wah’ tubes utilise fine thumb movement and so are chosen by patients wishing to strengthen this skill. Patients were encouraged to take instruments away with them between sessions and were given listening or creative tasks to facilitate continued work at home.

The pilot culminated in a celebratory public performance at Hull City Hall ahead of the RPO’s season opening concert, and thus provided an ultimate goal for each of the projects. The final project involved 3 days of standard workshops, followed by a fourth day which brought both participant groups together for a two-hour dress rehearsal before being transported to City Hall and performing in front of family, friends, invited guests and the general public.

Post-project evaluation and writing up followed from October to January 2016.

A programme timeline including the dates of all project activity is included in the following section. A full Programme Guide featuring detailed descriptions of the programme’s structure, musical content, instrument uses and logistical details is available upon request from resound@rpo.co.uk.



Figure 4 A patient works on standing at the tubular bells.

2.3 Timeline

Phase	Dates	Activity
Research & Development	November-December 2014	Review of existing literature
	10 December 2014	Development meeting
	15 December 2014	RPO/HICSS Practical Research Workshop Day 1
	19 February 2015	Development meeting
	20 February 2015	RPO/HICSS Practical Research Workshop Day 2. Included one-hour trial session with 5 patients.
Planning	March-May 2015	Development of pilot structure and schedule, arrangement of logistical details, recruitment of participants, collection of baseline data, formation of patient goals.
Pilot Project	28 & 29 May 2015	RPO Project 1. Included attendance at an RPO Open Rehearsal.
	5 June 2015	RPO Musician Training
	10 June 2015	HICSS Staff Training
	11 & 12 June 2015	RPO Project 2
	2 July 2015	HICSS Project 1
	16 & 17 July 2015	RPO Project 3
	30 July 2015	HICSS Project 2
	13 August 2015	HICSS Project 3
	20 & 21 August 2015	RPO Project 4
	17 September 2015	HICSS Project 4
	28 September – 1 October	RPO Project 5
Post-project Evaluation	October – November 2015	Patient and staff surveys and clinical data collection
	12 October 2015	Patient and staff focus group
	10 November 2015	RPO focus group
	November 2015 – January 2016	Analysis and writing up



2.4 Aims & Objectives

The pilot project incorporated a range of aims and objectives pertaining to the various stakeholders and aspects of a rehabilitation treatment programme:

RESEARCH & DEVELOPMENT

- To investigate the potential uses of different instruments and musical techniques to mimic, complement or even improve standard physical rehabilitation techniques.
- To evaluate the effects of group creative music-making sessions on the social and psychological recovery of stroke patients.
- To refine techniques for working with stroke patients in an inclusive, accessible and creative environment with intrinsic value to stroke recovery and artistic outcomes.
- To develop a sustainable, cost-effective model of group creative music therapy that supports the holistic rehabilitation of stroke survivors.

PATIENTS

- To contribute towards patients' physical, psychological, cognitive, functional, communication and wellbeing recovery.
- To empower patients to regain control of aspects of their lives through making artistic decisions and driving their own therapy goals and outcomes.
- To motivate patients to take ownership of and begin to self-manage their recovery.

CARERS

- To provide a period of respite for carers where clinical staff can take over their role.
- To improve physical, emotional and mental wellbeing for participating carers.
- To strengthen and improve relationships between carers and their relative.

CLINICAL STAFF

- To train HICSS staff in creative and musical leadership skills enabling them to utilize techniques and activities in interim projects and in their wider professional work.
- To raise staff morale and provide a fun and stress-reducing activity.
- To renew relationships between staff and their patients, by participating alongside them in an enjoyable activity.
- To challenge staff perceptions of patient abilities through supporting patient-led rehabilitation work.

ARTISTIC

- To produce meaningful pieces of music depicting the lives and experiences of Hull stroke survivors.
- To improve participants' musical skills including instrumental, rhythmic and creative abilities and confidences.
- To provide access to world-class musicians and encourage community engagement in music-making.

ARTS ORGANISATION

- To train RPO leaders and musicians to facilitate music workshops with measureable rehabilitation and health benefits.
- To increase project management expertise for the successful delivery of accessible creative therapy sessions.
- To support the RPO's residency at Hull City Hall, encouraging cultural uptake and contributing to placemaking in Hull.

3. Evaluating the Programme

A service evaluation of the project was completed to determine the effectiveness of the new intervention, following approval by the Humber NHS Trust Research and Development Department.

The pilot programme was designed to be inclusive of all stroke patients receiving care from HICSS and their carers, regardless of time after stroke, disability or level of recovery. As such, finding overarching evaluation methods to enable meaningful analysis of the progression of patients with a variety of goals and starting points was difficult. The evaluation therefore focused on the achievement of individual goals as the outcome.

3.1 Participant Statistics

A total of 50 unique patients and carers participated in at least one STROKESTRA session during the pilot phase. All participants were White British in ethnicity.

Type	Total	Females	Males	Median Age
Patients	33	13	20	66
Carers	17	11	6	60

There were a number of patient and carer dropouts throughout the programme. Reasons for patient drop out included unrelated illness or injury, scheduling issues and death. Reasons for carer drop out included their relative dropping out, as well as patients gaining confidence to begin attending sessions alone, allowing carers time away.

Data was collected and analysed from patients, carers and staff who maintained attendance and completed the STROKESTRA pilot in October 2015. Responses were therefore gathered from the following populations:

Type	Total	Females	Males	Median Age
Patients	21	9	12	66
Carers	7	5	2	60
Staff	10	10	0	41
RPO Musicians	7	2	5	43

3.2 Methodologies

Staff carried out a variety of qualitative and quantitative methods to analyse the effectiveness of the programme to meet its aims and objectives as well as patient needs. Measures include baseline and post-project Stroke Impact Scale scores, post-project evaluation surveys, focus groups, case studies, outcome measures specific to individual goals and financial assessments. See overleaf for a full description of each of the methods utilised.

Measure	Notes
Stroke Impact Scale	<p>Patients with the cognitive and language ability to complete the Stroke Impact Scale were assisted to complete the questionnaire at the time of joining the programme and following the completion of the pilot project in October (successful completion: n=17). The Stroke Impact Scale is a 59 item measure covering eight domains (physical strength, hand function, activities, mood, cognition, communication, mobility and participation). Each item is rated using a 5-point Likert scale in terms of the difficulty the patient has experienced in completing each item.</p> <p>Due to the diversity of the disabilities and goals of patients, there was great variability in scores for each domain. Due to this, and the small sample size, statistical comparison of the mean scores for each domain is inappropriate. It has been suggested that a difference of 10 points on the Stroke Impact Scale represents a clinically meaningful change (Duncan et al, 1999). The proportion of participants whose scores increased by at least 10 points was therefore calculated for each domain. See Appendices 7.2 and 7.3 for a reproduction and analysis of the Stroke Impact Scale.</p>
Other Clinical Tests	<p>Other clinical tests relevant to specific goals were administered to individual patients upon joining the programme and again following completion. Tests included the Patient Health Questionnaire (PHQ-9; n=2), General Anxiety Disorder scale (GAD-7; n=2), Communication Outcomes After Stroke scale (COAST; n=1), and Chedoke Upper Limb Assessment (n=1).</p> <p>Due to very few patients completing both baseline and post-project assessments on these clinical tests, their results are reported as case studies only and serve to illustrate the overarching outcomes rather than evidence impact on these clinical tests.</p>
Evaluation Interviews	<p>Semi-structured interviews were carried out with patients (n=21) upon completion of the pilot, asking patients to rate aspects and outcomes of the project on a 10-point Likert scale and provide additional comments. See appendix 7.4 for complete responses.</p>
Evaluation Surveys	<p>Tailored evaluation surveys were completed by participating carers (n=7) and HICSS staff (n=10), rating aspects and outcomes of the project on a 10-point Likert scale. See appendices 7.5 and 7.6 for complete responses.</p>
Patient & Carer Focus Group	<p>One two-hour focus group session with all patients and carers was facilitated to gather verbal feedback from participants following completion of the pilot. The session was recorded, transcribed and evaluated through a six-phase thematic analysis.</p>
RPO Focus Group	<p>One focus group with the full RPO team was carried out following the pilot programme to discuss the structure, therapy and artistic outcomes of the programme. The session was recorded, transcribed and evaluated through a six-phase thematic analysis.</p>
Case Studies	<p>Four case studies were prepared by HICSS staff from across disciplines to highlight exceptional cases of patient recovery. See Appendix 7.7 for full case studies.</p>
Financial Assessment	<p>A financial assessment of all costs (In Kind and incurred) was undertaken and analysed for potential savings in future projects.</p>



4. Findings

4.1 Impacts on patient physical recovery

71% of patients reported the project had benefited them physically, citing improved strength, increased use of affected hands/limbs, improved sleep quality, and increased flexibility, energy and stamina. Four out of seven carers agreed that they noticed physical improvement in the patient they cared for, referencing increased energy and use of affected limb(s) by patients as a result of the programme.

'[He] definitely had more energy; he was more relaxed. He definitely started using his [affected] arm more, for example he started using it when doing the washing.'

-Carer

56.3% of patients recorded an improvement of at least 10 points on the hand use section of the Stroke Impact Scale (SIS), while 33.3% of patients improved by at least this level in physical strength. One patient completed the Chedoke Upper Limb Assessment pre- and post-project, and reported a decreased level of difficulty and an increase in speed in completing all tasks following participation.

Several patients anecdotally reported increased use of their affected limb during daily activities, with added benefits to quality of life and return of independence.

'I was very weak on the left side and using the left side all the time [at sessions], I've got more strength in it. I can now hold things in this hand that I couldn't hold before. Especially, a cup of coffee, which is my favourite.'

-Patient

'I go out into my garage, I put my metal in the vice one-handed, I cut it, I put it in my drill and I'm using this [affected] hand on my saw to try and move it, so it's helping me and it's making me want to hold things ... while I do things with my good arm.'

-Patient

18.8% of patients improved by 10 points or more in the mobility section of the SIS. The act of preparing for and travelling to sessions accounted for some of these physical improvements including being motivated to stand and walk in order to access taxis and to take part in personal hygiene activities before sessions.

'Mobility wise, I had to force myself to stand and walk and sit in my wheelchair. It forced me to get a shower! I often don't because I have to rely on someone to help me.'

-Patient

'My walking is much better; I still use a stick but I don't feel as dependent on it.'

-Patient

Staff felt that the length of sessions, 2 hours compared to a normal 45-minute individual therapy session, allowed patients the opportunity to gain the necessary repetitions to make real improvements, with one Physiotherapist saying:

'I like the fact that we've got longer than a normal treatment session and you do a bit and have a rest and do a bit more. It takes about 400 repetitions to make a change in the brain let alone make a skilled movement – that's loads more – so the amount of repetitions that you clocked up is really good.'

Specific musical exercises during sessions also contributed to improved hand dexterity and arm strength due to an increase in use of affected limbs. Clinical staff observed that the repetition and rhythmic qualities of drum circles specifically contributed to increased upper limb rehabilitation work in patients:

'The drumming and the practicing rhythms seemed to be particularly engaging and useful for this. I can think of some people who appeared to manage more movement, more concentration, more tolerance relevant to their goals within the drumming and rhythm aspects of the project.'



Figure 5 A clinician helps a patient play the drum.

Staff also observed increases in upper limb movement and finger dexterity in patients playing electric guitar. One Occupational Therapist working alongside an upper limb patient learning the instrument observed::

'In earlier sessions the subject was unable to select and press strings to play chords without excessive shoulder hitching to compensate for lack of selective movement and dexterity. He reported a degree of discomfort and frustration when trying to select strings. Over time, with advice regarding technique and positioning/posture and some hand over hand guidance, he gradually improved and by the end could independently select strings and play with greater ease and satisfaction.'

Multiple patients cited increased relaxation as a result of the musical sessions, which they felt contributed to relief of post-stroke physical symptoms and an improvement in sleep quality and length.

'I suffer dizzy spells since my stroke and found these subsided when concentrating. I found the groups very relaxing.'

-Patient

'My sleeping improved very much. I found after the group I would sleep very well that night.'

-Patient

Overall, 31.3% of patients improved by a minimum of 10 points on the Activities section of the SIS, which asks about patients' abilities to complete daily activities such as getting dressed, cutting food, completing household chores and going shopping. The ability to carry out these activities contributes significantly to the independence and wellbeing of stroke survivors.

4.2 Impacts on patient cognitive recovery

86% of patients reported that the project benefited them cognitively with 11 patients citing improved concentration as a result of the focus required to successfully complete the musical activities.

'When I was playing an instrument or listening to the music, I was very focused. The group has definitely improved my concentration and attention.'

-Patient

'I had to concentrate a lot to remember rhythm, beat and timing.'

-Patient

Five patients reported their memory had improved throughout the project, including through remembering note patterns, rhythms or other musical devices, although one patient said that he still had difficulties remembering the patterns and tasks at the final performance.

Six out of seven carers completing evaluation surveys agreed that there had been improvements in concentration, memory, focus and attention to detail in their relative.

'[He's] more aware and can focus on different things.'

-Carer

43.8% of patients improved at least 10 points on the Cognition portion of the SIS, which determines patients' abilities to remember things that have happened or been said, concentrate, think quickly and solve problems.



Figure 6 A patient practices a melody on xylophone.



4.3 Impacts on patient social recovery

The social aspect of the music sessions became undeniably important for patients and carers as evidenced during the focus group session which continually referenced the importance of the 'family' feeling amongst the group and the 'teamwork' that went into the sessions. The importance of all members having been affected by stroke was paramount with the idea of having 'a common enemy and a common goal' amongst the stroke survivors and their carers.

'But I actually look forward to coming here, because as I say, we're a team. You know what I mean? You feel comfortable because nobody judges you. Nobody laughs, they might laugh with you but they don't laugh at you. So you're not going to embarrass yourself because if you do embarrass yourself it doesn't matter because it's fun.'

-Carer

'We all get pleasure, as well, to see other people who have had a stroke, how they're developing in the group.'

-Patient

91% of participants and 100% of carers reported that the project benefitted patients socially, both during music sessions and outside the group in community contexts.

'It forced me to go out and enjoy what was waiting at the other end. Because it was small doses a couple of hours and then back to safe zone, I could do it. I got home and thought "I could do that again". '

-Patient

'I live in sheltered accommodation and since the music group I have started to go in the common room and have coffee with others, which I never did.'

-Patient

62.5% of patients increased by at least 10 points on the Participation section of the SIS, assessing patients' confidence and ability to take part in hobbies and personal activities that help them find meaning in life.

15 patients cited social aspects of meeting other stroke survivors and creating new relationships as the most enjoyable part of the programme.

'I liked going out in the taxi, I enjoyed seeing people, people that I knew. I lost my confidence after a fall - now much better.'

-Patient

'Being part of the group and belonging to something.'

-Patient

100% of HICSS staff felt the project successfully supported social development in patients.

'For me it provided the opportunity for people to realise they can do things, go places and achieve just as they did before their stroke when given support to manage the effects of their disabilities. This is something that is VERY difficult to do for people who aren't going to do this anyway.'

-HICSS Staff

4.4 Impacts on patient emotional recovery

86% of patients agreed with the statement that the project benefited them emotionally, with 52% totally agreeing with this. Most patients cited improved mood as well as confidence and improved optimism for the future as the main emotional effects of the project.

'The music group sessions lifted my mood and gave me more confidence to have a go at anything.'

-Patient

'It brought me a little bit of myself back. It was the first time I had done something on my own since my stroke.'

-Patient

'If you have a stroke you think your life is completely over, because you can't do what you did before. But coming here you found out that you can do things and it's been very interesting. ... Everyone's the same, we've always got something, you know, different attitude and you know but actually everybody's got a big smile on their face these days, which they didn't have before.'

-Patient

43.8% of patients increased by at least ten points on the Mood section of the SIS, indicating lower levels of low mood and better control over their emotions. Additionally, the two patients completing the PHQ-9 depression and GAD-7 anxiety scales pre- and post-project recorded significant improvements in these areas as shown below.

Test	Patient 1 Pre	Patient 1 Post	Patient 2 Pre	Patient 2 Post
PHQ-9	24 out of 27	9 out of 27	16 out of 27	0 out of 27
GAD-7	9 out of 21	3 out of 21	8 out of 21	0 out of 21

Figure 6 Subjects 13 and 19 PHQ-9 and GAD-7 results. NB: Higher scores indicate greater depression and anxiety on these scales respectively.

All carers reported they agreed with the statement that there had been an emotional improvement in their relative during the project.

'It was the first time he was motivated, it was the first time he had socialised and it was the first time he wanted to do something after - we went out for tea. I think he put his embarrassment to one side. It was the first time I saw him smile in 3 months!'

-Carer

Patients also reported feeling able to return to non-musical hobbies they had previously abandoned due to the improved mood and motivation they felt during the music project. For instance, one patient returned to studying calligraphy, which he had abandoned feeling it was too difficult following his latest stroke, in order to complete a diary about his feelings and experiences of the music project.

02-07-15

Firstly I would like to thank each and everyone of you especially Michelle for bringing me out of hibernation and introducing me to a very talented group of people, mainly (R.P.O.)

I never realised just how much **Orchestral** music could communicate on a par with impressionist artists such as **Renoir, Monet, Degas** etc. In fact, I do believe it was **Claude Debussy & Maurice Ravel** who first introduced impressionism into music in the 1700's.

I've always had a passion for Heraldry but I'm no artist, I cannot play an instrument so, my only way of communicating in an artistic form is through :-



Calligraphy



Figure 7 Patients and carers interact with an RPO musician.

4.5 Impacts on patient communication recovery

35.3% of patients increased by at least 10 points on the SIS communication section completed pre- and post-project. Patients and carers cited improved understanding, an increase in fluency of speech and confidence to speak in front of others as a result of taking part in the project.

'Yes, I struggle with understanding of conversations, but as the group went on I found myself understanding more, and talking more.'

-Patient

'His speech improved. He started to speak on the phone; his boss frequently rang and I always talked, but after the project [he] started to have more input and speak on the phone.'

-Carer

The inclusion of patients with speech and language difficulties alongside patients experiencing other disabilities was cited as an important reason patients felt able to work towards speech goals, as they felt less embarrassed to work through difficulties.

'I met some wonderful people and met people who had also had strokes, which some had some of the same problems as me, so I didn't feel stupid if I could not find my word when talking.'

-Patient

Similarly, the musical focus of the group was considered very important in making patients with aphasia feel comfortable attending as they could relax and choose to speak or communicate through the music as they felt comfortable.

'The music helped me relax and not worry about communication.'

-Patient

'Because like music you don't have to have a voice, do you? Everybody can do it. So I don't know I suppose maybe you lose your embarrassment of not being able to do anything because you don't have to speak, you don't have to do anything other than play music.'

-Carer

One patient improved from 70% on the Communication After Stroke measure to 78% following participation in the project, while also scoring 10/10 on confidence when communicating. The same patient's SIS answers regarding difficulty communicating with others and understanding what is read or heard improved from 'very' or 'somewhat difficult' to 'not at all difficult' in all but one category.

In addition, patients with speech and language difficulties were observed to participate more in group discussions as the project progressed, with all SLT patients in attendance at the patient focus group speaking about their experience. One patient, speaking in front of the entire group of 28 people, said she *'didn't have the confidence 'til I came here'* to speak in public.

Patients, carers and staff during the evaluation focus group highlighted more opportunities for speech and language work as a potential improvement to future projects, including group singing and more small group activities to facilitate work in this area.



Figure 8 Clinical staff, patients and carers enjoy a rehearsal session.



4.6 Impacts on carers

Seven carers regularly attended music sessions alongside their relative while other carers supported their relative to attend alone, allowing them time to participate in activities of their own choosing. Evaluation surveys were completed by carers participating in music sessions only.

100% of participating carers agreed that the project gave them respite from their role as a carer by allowing them time off from worrying about their relative or care tasks. Focus group responses supported the idea that the sessions being supported by HICSS staff was important to this feeling of safety at sessions which allowed carers to unload their caring role onto the clinical team.

'I loved those two hours of being detached from my partner and let him do his own thing and I do my thing. It allowed me to be myself and socialise with everyone. Respite. Seeing my partner enjoy himself and I wasn't worrying about him.'

-Carer

All participating carers reported that the project had benefited their relationships with their relative.

'It was like courting all over again. I am telling him and communicating better with him even if it's in a bad way. I have started to realise he is still my partner...take that stroke bit away.'

-Carer

100% of carers also reported that participating alongside their partner in the project had improved their own personal wellbeing, with four of seven carers highlighting the opportunity to meet others in a similar position as very important. Responses also regularly referred to recovering a sense of self through the project.

'When someone has a stroke, the carers of people and the partners of people that have had strokes, your life changes. Their life changes a thousand times more but your life, my life as a partner as a wife as whatever, changed completely. And this is so important. I'm sorry I don't mean to be crying! It meant so much. I think it's so important.'

-Carer

'It made me feel I wasn't the only one in my position. Caring can be a lonely path at times and you can feel sad.'

-Carer

'It has motivated me to look at what is going on out there as far as hobbies, interests. It has opened my eyes. It's given me a bit of confidence. I'd forgotten what a bubbly outgoing person I was, I had forgotten who I was.'

-Carer

4.7 Impacts on clinical staff

The majority of HICSS staff could be considered apprehensive upon initially hearing about the project, due to reasons including personal confidence in delivering musical activity, understanding of the potential benefits for patients and trust in the artistic organisation to deliver an outstanding artistic piece with people with no musical training. Through staff training and successful RPO-led initial sessions, a core team of dedicated staff emerged who fully engaged with the programme.

'I do feel there was some uncertainty from a lot of the team in the early stages and this did add to apprehension with regards to staff morale. As the project got going and gathered momentum and the involved staff realised the positive effect within both process and product of the group, I feel it had a huge benefit to staff morale and sometimes in those who were perhaps the most cynical to start. It was such a pleasure to see both patient and staff mutually benefit being involved in something new, innovative and fun but also very therapeutic.'

–HICSS Staff

Following the project, 100% of participating staff said the project met their expectations, and staff confidence in the project achieving recovery goals improved in all areas. Upon completion, 100% of staff rated the project as successful supporting cognitive and social goals while 90% of staff felt the project was successful supporting physical and communicative goals.

90% of staff reported they got personal enjoyment out of the project. Other reported staff benefits included:

- Inspiration: 80%
- Team-working: 70%
- Team morale: 70%
- Musical ability: 60%
- Interest in music: 60%
- Renewed relationships with patients: 60%
- Adjusted expectations of patient abilities: 60%
- New ways of working: 60%
- Leadership skills: 50%
- Creativity: 50%

Two staff members highlighted how the music project enabled them to re-engage with their own musical interests, thus improving personal wellbeing. Multiple staff also reported feeling inspired by the project to evaluate how they can use creative, patient-centred techniques in their wider work.

'I found this project inspiring and energising. It has re-ignited my own personal interest in music, which has helped my wellbeing, health and ultimately my work. It has made me re-evaluate how we work with patients and the priorities we have and if we need to revisit these.'

-HICSS Staff

Many staff highlighted the power of the project to break down traditional barriers between themselves and the patients and carers they work with, due to participating alongside them at an activity they were not experts in.

'It is therapy that you can do together; both get involved in on an equal level. It knocks down all the boundaries, therapists and patients are all equal. The professional boundary wasn't there, it allowed the therapist to see a person rather than a person who had had a stroke, and the patient see them as an equal. With other therapy you have a teacher and a doer.'

-HICSS Staff

'[The most useful aspect of the project was] being an equal part in a group, learning music techniques and skills as an equal member of the group. It broke down the barriers of 'staff/patient'. Seeing patients laugh and enjoy and fully engage was fantastic and seeing people develop in confidence was brilliant.'

-HICSS Staff

This feeling was shared by carers and patients as this exchange from the patient focus group underlines:

- **Carer 1:** *Sometimes [people] find it difficult, don't they, to actually communicate and associate with therapists, same as doctor-patient. I mean you've got barriers, but I think this has actually broken those barriers down.*
- **Interviewer:** *So you're more comfortable with the therapists?*
- **Carer 1:** *Definitely. I mean I'm not the victim but you've got therapists coming into the home and definitely it's really changed me. A lot.*
- **Carer 2:** *We're a team now.*
- **Patient:** *Just like a massive circle of friends.*

Clinical staff were asked to fit the music sessions in alongside their normal patient schedules. As such, many staff fed back that the time required was stressful and difficult to arrange with their patient case-load. All staff fed back that a clear rota of staff needed for each session created well in advance would enable them to better arrange their own schedules, ensure a wider variety of therapy disciplines were involved and facilitate a more equal sharing of hours amongst staff members. Staff also agreed further training and sharing of responsibility with HICSS Associate Practitioners would lead to reduced burdens on therapist time and expertise while empowering more junior members of staff to gain leadership and management experience.



Figure 9 An Occupational Therapist works with a patient.

4.8 Impacts on artistic skills

76% of patients and 90% of carers agreed that the project had changed the way they listen to music. All patient comments on this area highlighted an increase in awareness when hearing music, even in film soundtracks or while shopping, and an increased ability to pick out specific instruments and lines.

'When watching TV, I hear the music more in the background where as previously wouldn't have noticed.'

-Patient

'If I put a CD on I'm listening more intently now (e.g. Andrea Bocelli, Katherine Jenkins). Listen to the music now not just singing. It's a good thing and educational – picking certain parts of the music out. Even if a cowboy film is on, I listen to the music.'

-Patient

'I'm listening to things that I've not heard before that have always been there and it's really opened me up and I really love it. It's got me here somewhere, you know, in the heart.'

-Patient

RPO musicians noticed a marked difference in the group's general music abilities from the beginning to the end of the pilot programme, including listening to each other, playing as an ensemble, repeating patterns, and improved aural memory. Patients and carers also displayed learned preferences for specific instruments by the end of the pilot, carefully selecting instruments and beaters to achieve their desired sound or impact.

All patients and carers attending the focus group session expressed feelings of artistic ownership of their musical creations, reporting pride in performing in front of friends and family, pride in correctly remembering musical passages and techniques and offering suggestions for future musical pieces.

'But I would have never have thought it would sound like that. As a tune, I mean it was actually a piece of music. We actually put together two pieces of music, which I would've, when we were listening especially at the rehearsal when we were practicing I mean, good God, some of the noises...But you never thought it would come out like that.'

-Carer

Three patients expressed interest in continuing to learn instruments through private lessons with one patient desiring to learn to read music. Patients also expressed an interest in joining other community music groups, once they have successfully achieved their goals supported by STROKESTRA. Since the pilot completion, one patient has purchased a cello and begun learning to play and read music alongside their grandchild.

Multiple carers also developed interests in learning musical instruments, with one carer purchasing a clarinet during the sessions and another looking up flute lessons following completion.

4.9 Economic evaluation

The pilot project was funded with a £48,000 grant from Public Health Hull which covered all research & development, delivery, evaluation, dissemination and extension project costs. HICSS staff time was integrated into their normal working hours, so that this project expenditure included only aspects of RPO musician delivery, venue hire, marketing, patient transport, instrument purchase and project management.

Clinical staff numbers fluctuated throughout the pilot programme as the partners decided how many staff were necessary to maintain safe staffing levels. At the end of the pilot project it was agreed that sessions with up to 25 patients could go forward with a minimum of one Qualified Therapist (Band 6), four Associate Practitioners (Band 4) and one Administrative Liaison (Band 2 or 3). Daily costs of these staff therefore amount to an average of £551.96 of In Kind support per project day. Additional time was also given In Kind by key staff involved in the research, planning and evaluation of the pilot programme.

A five-month programme equivalent to the pilot programme equates to actual expenditure of £32,756. This amount includes costs of one training session for HICSS staff, thirty hours of intensive creative therapy for up to fifty patients, opportunities to attend open rehearsals to observe the full Royal Philharmonic Orchestra in live rehearsal, purchase and provision of instruments, 'homework' to facilitate further therapeutic hours practicing and listening in between sessions, and a large-scale public performance alongside members of the Royal Philharmonic Orchestra. This amounts to expenditure of just over £655 per patient, or just £22 per therapy hour, making the STROKESTRA model extremely cost effective when considering its ability to provide so many hours of patient-led, therapist-supported, holistic stroke recovery for stroke patients and carers.



Figure 10 Patients, carers and clinical staff follow Workshop Leader Tim Steiner.



Lomax

5. Discussion

5.1 Outcome themes

The STROKESTRA pilot project was successful in supporting stroke recovery for all patients that attended, and achieving positive change across physical, emotional, cognitive, functional, social and communicative domains. Many patients also showed more global improvement, which was not specifically related to their stated goals, showing the project was successful in supporting holistic recovery. Further outcomes included respite and improved wellbeing for carers, renewed relationships between carers and their relatives, inspiration and team morale boosts for HICSS staff, and consolidation of expertise for the RPO.

It took time for patients, carers and HICSS staff to feel comfortable participating and to understand the potentials of the programme. Buy-in to the programme from all stakeholders was extremely important to the success of the project. Future projects should therefore aim to integrate patient-led recruitment strategies and provide ample training and observation time for new staff, ensuring positivity and compliance are present in the initial stages.

Meeting others who have experienced stroke was an important factor in most patient and carer feedback, highlighting the power of bringing people in similar situations together for group therapy. The ability of the programme to create a 'team' feeling amongst all participants supported patients to work towards therapy goals without embarrassment and with support from others experiencing similar challenges. The development of new relationships free of judgment or a caring responsibility also contributed greatly to improved wellbeing for patients and carers alike.

67% of patients felt the impacts of the programme carried on after the sessions themselves ended, highlighting the potential of the programme to support long-term recovery and self-management.

62% of patients agreed that the project gave extra benefits compared to other forms of therapy they have tried. The musical aspects were both enjoyable and practical, offering escape from normal therapy as well as providing the motivation to continue rehabilitation work where other therapies may fail. The immediacy of creating sounds on musical instruments offered instant feedback to patients about the accuracy of their movements or speech, and the feeling of being part of a group was immediately accessible through facilitated group activities. Delivering the therapy through expert musicians supported by clinical staff enabled the sessions to feel safe and sustained by clinical guidance, whilst enabling clinical staff, patients and carers to all be musical learners. As all participants took part in musical work, this broke down the normal hierarchical social and therapy structures, which proved powerful in improving relationships between therapists, carers and patients, and qualitative reports suggest it may have contributed to the willingness of patients to try new techniques that carried a risk of failure.

Artistically the programme achieved outstanding results, with the STROKESTRA ensemble performing two original pieces of music to a public audience at Hull City Hall on 1st October 2015, after only five months of sessions. The pieces were emotionally affecting, structurally interesting and finely executed, and were well-received by audiences. Following this initial performance, the group was invited to perform at the Humber NHS Staff Awards in December 2015 to share their artistic and rehabilitative successes with the full NHS staff.

5.2 Limitations

Because the project was designed to include any HICSS patient regardless of time after stroke, disability or recovery goals, it was difficult to devise over-arching evaluation methods that could capture the progress of a large enough sample of patients to be meaningful. The varying cognitive and communicative abilities of patients also meant that specific methods were not suitable for some patients and would need to be modified or delivered in a different way to the rest of the group.

The Stroke Impact Scale (Version 3.0) was chosen to measure holistic effects, due to its focus on a range of aspects of life after stroke; however it was felt that the scale was not sensitive enough in many areas relevant to specific patient goals, and therefore small but significant changes in patient progression were almost certainly missed. (There is no valid and reliable measure which would both capture small, important, individual change, as well as the gross impact on life after stroke.) Additionally, as patients set their own individualised recovery goals to work towards during the project, not all areas of the Stroke Impact Scale may have been relevant to a patient's progress during the project, meaning mean scores may be misleading due to a patient not having focused on an area. However, staff agreed the SIS was a good measure for catching overall outcomes and results, and useful in charting changes in recovery areas that patients may not have anticipated.

The staff time required to ensure baselines and post-project evaluation methods were completed successfully was difficult to arrange due to staff needing to fit these sessions in around already-full case loads. While many patients would have benefitted from individualised clinical tests relevant to goals before and after the project, lack of staff time to carry these out meant that very few tests were successfully completed, leading to a failure to yield meaningful results relevant to the project as a whole.

Due to the pilot nature of the project, clinical staff were initially unsure of the potential of the project and were therefore less able to support patients to choose appropriately challenging goals before sessions began. This meant that patient goals were sometimes unclear and liable to change during sessions, as staff and patients understood more fully what could be achieved.

Sessions were designed to be engaging, creative workshops supporting high-quality music-making. In some instances, the desire to perform musical techniques accurately may have impacted on patients' willingness to work towards stated physical recovery goals by using affected limbs or movements they found difficult. Though musical success can play a role in patient enjoyment of sessions - a valid and important aspect of teambuilding, emotional and psychological recovery of patients - it is important to remind patients that they aren't expected to achieve complete mastery of techniques during an individual session, but rather to work towards success by the final performance.

Initial questions regarding the sharing of patient data with the artistic staff members naturally arose. It was decided that the patients' informed consent allowed pertinent data to be shared with artistic staff, although in reality only general information such as primary disabilities and goals for each patient was necessary for the artistic team to successfully deliver sessions.



5.3 Future plans

The success of the pilot programme in supporting positive recovery in patients, carers and clinical staff highlights the need for on-going plans to develop and expand the STROKESTRA model. HICSS and the RPO are currently planning a 3-year programme to address the outcomes of this evaluation report, including opportunities for further robust clinical evaluation.

A 3-year programme will feature a total of six two 'terms' of activity lasting five months each, with two terms delivered per year. Each term will operate a similar structure to the pilot programme, with alternating sessions led by the RPO team and specially trained HICSS staff. The long-term planning will allow patients to participate over more than one term, allowing opportunities to work towards complex goals after initial gains in mood, wellbeing and social recovery have taken place.

These sessions will incorporate the musical techniques from the pilot project, whilst also including adjusted techniques designed to offer more speech and language rehabilitation work. Singing, song writing and small group work encouraging further focus on SLT recovery will be included as suggested by this evaluation.

The long-term programme will also aim to recruit more participants through the creation of patient-led marketing materials, using real patient and carer testimonials and images/video to reassure prospective patients about the programme. Sessions will also be taken into community rehabilitation units for patients who have not yet returned home. These sessions will allow staff to evaluate the effectiveness of the rehabilitation model on patients immediately after stroke, as well as create a link between hospital and community care, with patients invited to attend community sessions following their discharge.

Partnerships with Hull University will provide opportunities for training students in musical outreach and increase their awareness of stroke, and will enable music students to support more regular delivery in wards and community settings. Health and research students may also be approached to gain experience delivering and evaluating the intervention with stroke patients.

The multi-year programme will facilitate a focus on progression routes for patients and carers aimed at delivering greater independence and quality of life post-STROKESTRA:

1. Patients and carers will be given the opportunity to take on more responsibility within STROKESTRA following successful completion of a term of activity as volunteers responsible for assisting with non-clinical roles of sessions. Responsibilities will include setting up the performance area, preparing tea and coffee and supporting patients during break times, and are designed to improve wellbeing through added purpose, responsibility and an opportunity to give back to others as part of a community.
2. Local community music organisations will be approached, and appropriate groups will be invited to deliver 'taster' sessions during HICSS-led project sessions to introduce patients to external music groups in a safe environment. All patients will be signposted to and supported to register with local community groups to facilitate greater community engagement following completion of two terms of STROKESTRA.
3. Interested individuals will be supported to fundraise for and purchase personal instruments and private tuition to continue their personal music development during and after their STROKESTRA involvement.

The programme will also offer progression routes for HICSS staff by providing termly training by RPO staff to continue to develop music and leadership qualities. More responsibility for the daily running of sessions will be turned over to Associate Practitioners, with one AP assigned as 'co-ordinator' of each session and tasked with managing the HICSS team and overseeing the smooth running of sessions for patients, carers, staff and volunteers. While Qualified Therapists will continue to oversee the assessments, creation of goals and treatment plans, these responsibilities will give Associate Practitioners areas for growth in leadership and management.

Finally, the partners aim to employ an external evaluator to allow for more robust evaluation of the effects of the programme on patients, carers and staff. Using third party researchers will allow for more time to be taken to collect clinical baseline and post-project data including specific upper limb, speech and language, and mood assessments. Given the length of the proposed programme, research will also look to examine longitudinal outcomes, assessing whether and how the positive effects are maintained after patients complete their STROKESTRA participation.



Figure 11 An RPO violinist and HICSS Occupational Therapist laugh before a STROKESTRA performance.

6. References

- Adamson, J., Beswick, A., & Ebrahim, S. (2004). Is Stroke the Most Common Cause of Disability? *Journal of Stroke Cerebrovascular Diseases*, 13(4), 171-177.
- Altenmüller, E., Marco-Pallares, J., Münte, T.F., & Schneider, S. (2009). Neural Reorganization Underlies Improvement in Stroke-induced Motor Dysfunction by Music-supported Therapy. *Annals of the New York Academy of Sciences*, 1169, 395-405.
- Amengual, J. L., Rojo, N., Veciana de las Heras, M., Marco-Pallarés, J., Grau-Sánchez, J., Schneider, S., [...] & Rodríguez-Fornells, A. (2013). Sensorimotor Plasticity after Music-Supported Therapy in Chronic Stroke Patients Revealed by Transcranial Magnetic Stimulation. *PLoS ONE*, 8(4), e61883. doi:10.1371/journal.pone.0061883
- Antić, S., Galinović, I., Lovrenčić-Huzjan, A., Vuković, V., Jurašić, M., & Demarin, V. (2008). Music as an Auditory Stimulus in Stroke Patients. *Collegium Antropologicum*, 32, 19-23.
- Belin, P., Van Eeckhout, P., Zilbovicius, M., Remy, P., François, C., Guillaume, S., [...] & Samson, Y. (1996). Recovery from nonfluent aphasia after melodic intonation therapy: a PET study. *Neurology*, 47(6), 1504-1511.
- Bradt, J., Magee, W.L., Dileo, C., Wheeler, B.L., & McGilloway, E. (2010). Music therapy for acquired brain injury. *Cochrane Database Systematic Reviews*, 7(7):CD006787. Doi: 10.1002/14651858.CD006787.pub2.
- Breier, J., Randle, S., Maher, L., & Papanicolaou, C. (2010). Changes in maps of language activity activation following melodic intonation therapy using magnetoencephalography: Two case studies. *Journal of Clinical and Experimental Neuropsychology*, 32(3), 309-314.
- Chen, M.C., Tsai, P.L., Huang, Y.T., & Lin, K.C. (2013). Pleasant music improves visual attention in patients with unilateral neglect after stroke. *Brain Injury*, 27(1), 75-82.
- Duncan, P. W., Wallace, D., Lai, S.M., Johnson, D., Embretson, S., & Laster, L.J. (1999). The stroke impact scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. *Stroke*, 30(10), 2131-2140.
- Forsblom, A., Laitinen, S., Särkämö, T., & Tervaniemi, M. (2009). Therapeutic Role of Music Listening in Stroke Rehabilitation. *Annals of the New York Academy of Sciences*, 1169(1), 426-430.
- Fukui, H. and Toyoshima, K. (2008). Music facilitates the neurogenesis, regeneration and repair of neurons. *Medical Hypotheses*, 71, 765-769.
- Grau-Sánchez, J., Amengual, J.L., Rojo, N., Veciana de las Heras, M., Montero, J., Rubio, F., Altenmüller, E., Münte, T., & Rodríguez-Fornells, A. (2013). Plasticity in the sensorimotor cortex induced by Music-supported therapy in stroke patients: a TMS study. *Frontiers in Human Neuroscience*, 7(494), 1-11.
- Guétin, S., Soua, B., Voiriot, G., Picot, M.C., & Hérisson, C. (2008). The effect of music therapy on mood and anxiety-depression: An observational study in institutionalised patients with traumatic brain injury. *Annals of physical and rehabilitation medicine*, 52(1), 30-40.
- Habron, J., Butterfly, F., Gordon, I., & Roebuck, A. (2013). Being Well, Being Musical: Music Composition as a Resource and Occupation for Older People. *British Journal of Occupational Therapy*, 76(7), 308-316.
- Hackett, M.L., Yapa, C., Parag, V., & Anderson, C.S. (2005). Frequency of depression after stroke: a systematic review of observational studies. *Stroke*, 36(6), 1330-1340.

Health and Social Care Information Centre. (2015). Quality and Outcomes Framework (QOF) - 2014-15. Retrieved from <http://www.hscic.gov.uk/catalogue/PUB18887>

Hurkmans, J., de Bruijn, M., Boonstra, A.M., Jonkers, R., Bastiaanse, R., Arendzen, H., & Reinders-Messelink, H. (2012). Music in the treatment of neurological language and speech disorders: A systematic review. *Aphasiology*, 26(1), 1-19.

Jamali, S., Fujioka, T., & Ross, B. (2014). Neuromagnetic beta and gamma oscillations in the somatosensory cortex after music training in healthy older adults and a chronic stroke patient. *Clinical Neurophysiology*, 125(6), 1213-1222.

Kim, D.S., Park, Y.G., Choi, J.H., Im, S-H., Jung, K.J., & Cha, Y.A. (2011) Effects of Music Therapy on Mood in Stroke Patients. *Yonsei Medical Journal*, 52(6), 977-981.

Lim, B.K., Kim, Y-K., Lee, H-J., Yoo, J., Hwang, J.Y., Kim, J-A., & Kim, S-K. (2013). The Therapeutic Effect of Neurologic Music Therapy and Speech Language Therapy in Post-Stroke Aphasic Patients. *Annals of Rehabilitation Medicine*, 37(4), 556-562.

National Institutes of Health. (2014). Post-Stroke Rehabilitation Fact Sheet. Retrieved from <http://stroke.nih.gov/materials/rehabilitation.htm>

National Health Service. (2014). Stroke. Retrieved from <http://www.nhs.uk/conditions/Stroke/Pages/Introduction.aspx>

Nayak, S., Wheeler, B.L., Shiflett, S., & Agostinelli, S. (2000). Effect of music therapy on mood and social interaction among individuals with acute traumatic brain injury and stroke. *Rehabilitation Psychology*. 45(3), 274-283.

Poćwierz-Marciniak, I. (2014). Music Therapy in the Rehabilitation of a Stroke Patient. *Acta Neuropsychologica*, 12(1), 85-102.

Raglio, A., Fazio, P., Imbriani, C., & Granieri, E. (2013). Neuroscientific basis and effectiveness of music and music therapy in neuromotor rehabilitation. *Alternative Medicine*, 1(1), 8.

Rodriguez-Fornells, A., Rojo, N., Amengual, J.L., Ripollés, P., Altenmüller, E., & Münte, T.F. (2012) The involvement of audio-motor coupling in the music-supported therapy applied to stroke patients. *Annals of the New York Academy of Sciences*, 1252, 282-293.

Royal College of Physicians. (2015). Sentinel Stroke National Audit Programme (SSNAP) Clinical audit April - June 2015 public report. Retrieved from <https://www.strokeaudit.org/Documents/Results/National/AprJun2015/AprJun2015-PublicReport.aspx>

Saka, O., McGuire, A., & Wolfe, C. (2009). Cost of stroke in the United Kingdom. *Age and Ageing*, 38(1), 27-32.

Särkämö, T., Tervaniemi, M., Laitinen, S., Forsblom, A., Mikkonen, M., Autti, T., Silvennoinen, H.M., [...] & Hietanen, M. (2008). Music listening enhances cognitive recovery and mood after middle cerebral artery stroke. *Brain*, 131(Pt 3), 866-876.

Särkämö, T. and Soto, D. (2012). Music listening after stroke: beneficial effects and potential neural mechanisms. *Annals of the New York Academy of Sciences*, 1252, 266-281.

Särkämö, T., Ripollés, P., Vepsäläinen, H., Autti, T., Silvennoinen, H.M., Salli, E., Laitinen, S., Forsblom, A., Soinila, S., & Rodriguez-Fornells, A. (2014). Structural changes induced by daily music listening in the recovering brain after middle cerebral artery stroke: a voxel-based morphometry study. *Frontiers in Human Neuroscience*, 8, 245.

Schneider, S., Schönle, P.W., Altenmüller, E., & Münte, T.F. (2007). Using musical instruments to improve motor skill recovery following a stroke. *Journal of Neurology*, 254(10), 1339-1346.

Schneider, S., Münte, T., Rodriguez-Fornells, A., Sailer, M., & Altenmüller, E. (2010). Music-Supported Training is More Efficient than Functional Motor Training for Recovery of Fine Motor Skills in Stroke Patients. *Music Perception: An Interdisciplinary Journal*, 27(4), 271-280.

Stroke Association. (2013). Feeling Overwhelmed: The emotional impact of stroke. Retrieved from https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web.pdf

Thaut, M.H., Gardiner, J.C., Holmberg, D., Horwitz, J., Kent, L., Andrews, G., Donelan, B., & McIntosh, G.R. (2009). Neurologic Music Therapy Improves Executive Function and Emotional Adjustment in Traumatic Brain Injury Rehabilitation. *The Neurosciences and Music III: Disorders and Plasticity*, 1169, 406-416.

Thaut, M.H. and McKintosh, G.C. (2014). Neurologic Music Therapy in Stroke Rehabilitation. *Current Physical Medicine and Rehabilitation Reports*, doi 10.1007/s40141-014-0049-y

Thornberg, K., Josephsson, S. & Lindquist, I. (2014). Experiences of participation in rhythm and movement therapy after stroke. *Disability Rehabilitation*, 36(22), 1869-1874.

Tsai, P.L., Chen, M-C., Huang, Y-T., Lin, K-C., Chen, K-L., & Hsu, Y-W. (2013). Listening to Classical Music Ameliorates Unilateral Neglect After Stroke. *American Journal of Occupational Therapy*, 67, 328-35.

Van Wijck, F., Knox, D., Dodds, C., Cassidy, G., Alexander, G., & MacDonald, R. (2012). Making music after stroke: using musical activities to enhance arm function. *Annals of the New York Academy of Sciences*, 1252, 305-311.

Wheeler, B., Shiflett, S.C., & Nayak, S. (2003). Effects of Number of Sessions and Group or Individual Music Therapy on the Mood and Behaviour of People Who Have Had Strokes or Traumatic Brain Injuries. *Nordic Journal of Music Therapy*, 12(2), 139-151.

Wolf, S.L., Winstein, C.J., Miller, J.P., Thompson, P.A., Taub, E., Uswatte, G., Morris, D., Blanton, S., Nichols-Larsen, D., & Clark, P. (2008). The EXCITE Trial: Retention of Improved Upper Extremity Function Among Stroke Survivors Receiving CI Movement Therapy. *The Lancet Neurology*, 7(1), 33-40.

Appendix 7.1 – Full Outcome List



STROKESTRA: Full Outcome List

The activities of the STROKESTRA programme are designed to address the following stroke recovery outcomes:

Patients

- Physical
 - Muscle strength (hands/arms/legs/core)
 - Range of motion (wrists/elbows/shoulders/hips/neck/knees/ankles)
 - Improved pain management
 - Relief of spasticity
 - Coordination
 - Core stability
 - Balance
 - Mobility
 - Finger dexterity
 - Functional movement (eg. reach, grasp, release)
 - Sensation
 - Breath support
 - Sleep quality
- Cognitive
 - Memory
 - Concentration
 - Planning
 - Sequencing
 - Motor planning
 - Insight
 - Problem solving
 - Abstract reasoning
 - Orientation
 - Attentional switching
 - Sensory awareness
- Communication
 - Increased confidence in speaking 1:1 and in group settings
 - Increased confidence in communicating with unfamiliar people
 - Increased confidence in using strategies to support communication
 - Opportunities for nonverbal communication and expression through music
 - Improved receptive language (eg. following instructions)
 - Improved listening skills
 - Improved expressive language through sharing information, speaking with other group members
 - Improved abilities to understand and describe concepts (eg. louder, quieter, slower, faster, etc.)
 - Opportunities to improve writing skills through completion of reflective diary

Appendix 7.1 – Full Outcome List

- Social
 - Socialisation
 - Confidence in group situations
 - New relationships
 - Improved relationships between carers and patients
 - Improved relationships between patients and HICSS staff
- Emotional
 - Improved mood
 - Enjoyment
 - Reduced feelings of depression
 - Facilitation of adjustment to their symptoms and change in life resulting from stroke
 - Increased feelings of worth and/or purpose
 - Reduced feelings of anxiety
 - Self-expression
 - Confidence
 - Empowerment – both to create their own music and to take control of their personal rehabilitation
 - Increased feelings of independence
 - Development of new interests and hobbies
- Musical
 - Knowledge of instruments, orchestral repertoire and musical terms
 - Rhythm
 - Creativity
 - Instrumental and singing skills
 - Performance and confidence skills

Carers

- Respite from role as a carer
- Enjoyment of an activity for themselves (if taking part)
- Renewed relationship with patient based on equal power balance and joint activity
- Creativity and musical development
- Relationships with other carers in similar situations
- Facilitation of adjustment to their family member's symptoms and change in life resulting from stroke
- Improved relationships between carers and HICSS staff

HICSS Staff

- Enjoyment
- Staff morale for team of deliverers
- Renewed relationship with patients based on side-by-side participation
- Personal musical development
- Musical leadership development
- Personnel management development for junior staff
- Creativity

RPO Team

- Enjoyment
- Sense of giving back to communities that support them
- Creativity
- Knowledge about stroke and disabilities
- Support for concert residency by engaging wider community

Stroke Impact Scale

VERSION 3.0

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from **YOUR POINT OF VIEW** how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.

Stroke Impact Scale

These questions are about the physical problems which may have occurred as a result of your stroke.

1. In the past week, how would you rate the strength of your...	A lot of strength	Quite a bit of strength	Some strength	A little strength	No strength at all
a. Arm that was <u>most affected</u> by your stroke?	5	4	3	2	1
b. Grip of your hand that was <u>most affected</u> by your stroke?	5	4	3	2	1
c. Leg that was <u>most affected</u> by your stroke?	5	4	3	2	1
d. Foot/ankle that was <u>most affected</u> by your stroke?	5	4	3	2	1

These questions are about your memory and thinking.

2. In the past week, how difficult was it for you to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

Appendix 7.2 – Stroke Impact Scale

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

3. In the past week, how often did you...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

4. In the past week, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialling?	5	4	3	2	1

Appendix 7.2 – Stroke Impact Scale

The following questions ask about activities you might do during a typical day.

5. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

The following questions are about your ability to be mobile, at home and in the community.

6. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

Appendix 7.2 – Stroke Impact Scale

The following questions are about your ability to use your hand that was **MOST AFFECTED** by your stroke.

7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

8. During the past 4 weeks, how much of the time have you been limited in...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Your work (paid, voluntary or other)	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wish?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1

Appendix 7.2 – Stroke Impact Scale

9. Stroke Recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?

_____ 100 Full Recovery

—
_____ 90

—
_____ 80

—
_____ 70

—
_____ 60

—
_____ 50

—
_____ 40

—
_____ 30

—
_____ 20

—
_____ 10

_____ 0 No Recovery

Appendix 7.3 – Stroke Impact Scale – Analysis

Stroke Impact Scale - Analysis

Participants with the cognitive and language ability to complete the Stroke Impact Scale were asked to complete this questionnaire as a baseline and outcome measure. The stroke Impact Scale is a 59 item measure covering eight domains (physical strength, hand function, activities, mood, cognition, communication, mobility and participation). Each item is rated using a 5-point Likert scale in terms of the difficulty the patient has experienced in completing each item. Summative scores are generated for each domain with scores ranging from 0-100. Seventeen group members completed the Stroke Impact Scale.

Domain	Pre-project mean (sd)	Post project mean (sd)
Physical Strength	44.1 (21.7)	42.3 (18.0)
Cognition	52.6 (15.4)	61.6 (14.9)
Mood	59.1 (15.7)	63.4 (14.2)
Communication	63.4 (19.2)	70.1 (13.6)
Activities	43.5 (15.4)	50.8 (18.3)
Mobility	46.3 (20.1)	49.6 (20.6)
Hand use	20.6 (21.1)	30.1 (31.7)
Participation	32.0 (18.6)	44.6 18.3)

Due to the diversity of the difficulties and abilities of the group members, there was great variability in scores for each domain. Due to this, and the small sample size, statistical comparison of the mean scores for each domain is inappropriate. It has been suggested that a difference of 10 points on the Stroke Impact Scale represents a clinically meaningful change (Duncan et al., 1999). The proportion of participants whose scores increased by at least 10 points was therefore calculated for each domain.

Domain	Percentage of participants whose score increased by at least 10 points
Physical Strength	33.3
Cognition	43.8
Mood	43.8
Communication	35.3
Activities	31.3
Mobility	18.8
Hand use	56.3
Participation	62.5

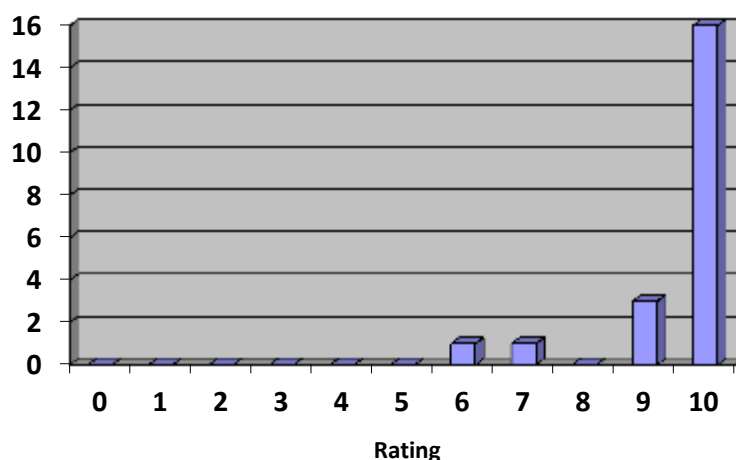
Appendix 7.4 – Patient evaluation survey and full responses



Patient evaluation survey

Patients rated on the scale of 0-10 the degree to which they agreed or disagreed with the following statements (where 0 = do not agree at all; 5 = neither agree nor disagree and 10 = totally agree).

1. I have found the music project enjoyable



All participants rated the project as enjoyable, with 76% rating this statement as a 10 (totally agree). Comments included:

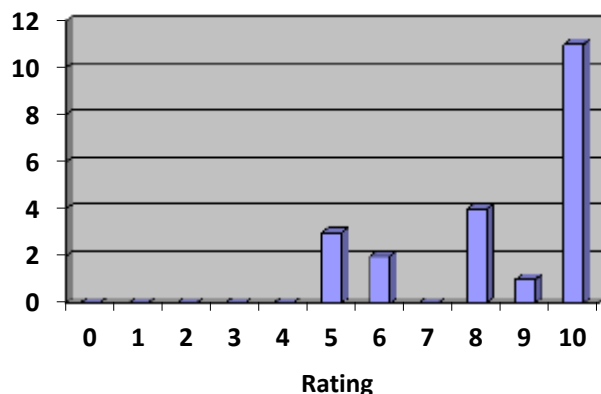
- 'Fantastic'
- 'Brilliant'
- 'Excellent from start to finish'
- 'Riveting'
- 'Very enjoyable'
- 'I enjoyed every minute of it'

The reasons people gave include:

- 'Think about stroke all the time, music project was able to keep my mind occupied'
- 'I like meeting people there'
- 'Nice to be involved in a group with the same sort of problems'
- 'Lifted mood, something to look forward to and gave me something to do'
- 'Very relaxing'
- 'I enjoyed meeting other people who had suffered strokes, I loved the different instruments'
- 'We have had the time of our lives'
- 'It was something to look forward to'

Appendix 7.4 – Patient evaluation survey and full responses

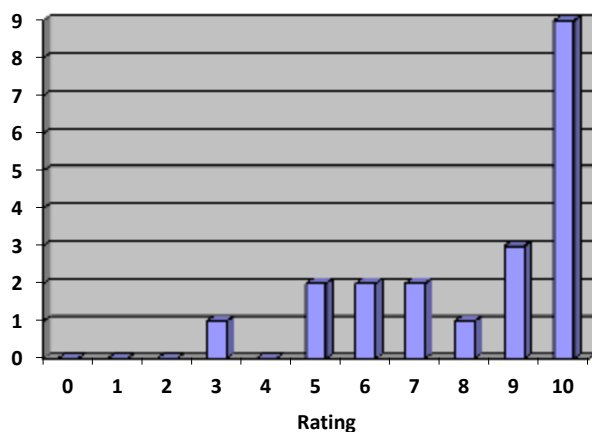
2. I have found the music project useful



All participants rated the project as useful, with 52% rating this statement as 10 (totally agree).

- 'Wonderful friends met, nice to get involved in the group, wonderful people'
- 'Listening to more music, also able to use affected hand more with instruments'
- 'Speaking, interacting with other people'
- 'It helped me with concentration'
- 'Helped me work towards my goal of using my hand more, concentrating, thinking about things and helped with mood'
- 'I was able to relax more and feel it improved my confidence being around people in a group'
- 'Listening to different music, never would have normally listened to classical music'
- 'It gives you an aim, to go for something. It gives you some motivation-you have to get up and go'
- 'We have found so many benefits with all aspects of the scheme'
- 'I have found I am speaking better. My communication in a group setting was poor, but it feels it's very much improved'
- 'It got me out'
- 'It was all useful, you learn a little bit more each time. I was learning as I went along, things I wouldn't have thought of like conducting the orchestra-they're not a big thing, but it was useful'
- 'It forced me to go out and enjoy what was waiting at the other end. Because it was small doses a couple of hours and then back to safe zone, I could do it. I got home and thought "I could do that again"'

3. The music project has enhanced my ability to achieve my stroke recovery goals



Appendix 7.4 – Patient evaluation survey and full responses

86% of participants reported that the project enhanced their ability to achieve their stroke recovery goals. 42% of participants totally agreed with this statement.

Those that reported the project enhanced their ability to achieve their goals said:

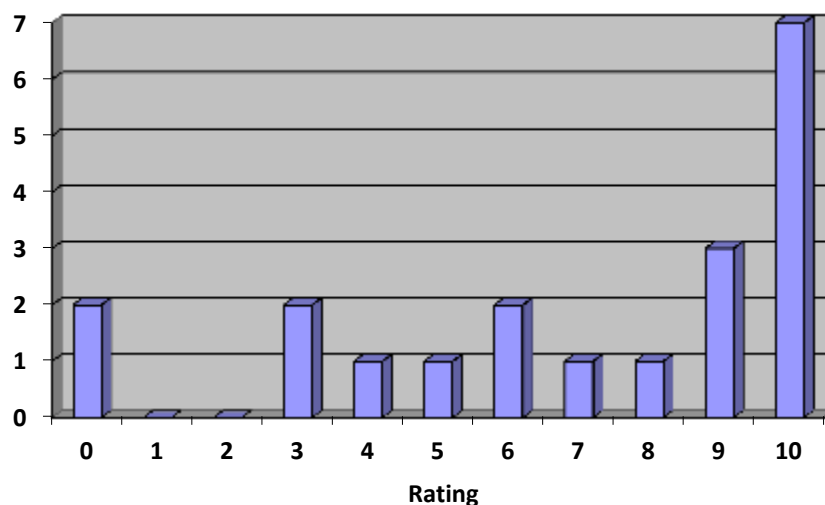
- 'Walking better, church floor is flat, standing more, concentration slightly better, benefitted me mentally and more confident, I used to be shy'
- 'It helped my outlook on things, it's marvellous!'
- 'Using my affected hand with instruments more and gave me more confidence around people'
- 'Speaking in a group'
- 'Strength in left hand and arm'
- 'Concentrating, mood and hand'
- 'Helped my confidence as lost a lot of confidence after my stroke, also helped my concentration'
- 'My confidence has grown, and confidence in being around other people. I feel back to my old self'
- 'Things in general'
- 'Mobility, social skills'
- 'Yes, increased my confidence in speaking with others'
- 'My communication goals the project has improved and my walking. I feel more confident in group settings'
- 'Not for goals of being able to walk again but did help goal of going out'

The two people who said they neither agree nor disagree with the statement made the following comments:

- 'Would have done if I had started later, was too soon after the stroke'
- 'Not totally sure what my goals were'

The one person who rated that they did not agree with the statement commented that they had not achieved their goal of 'improving speech'.

4. The music project has benefited me physically (e.g. mobility, energy levels, arm function, sleep)



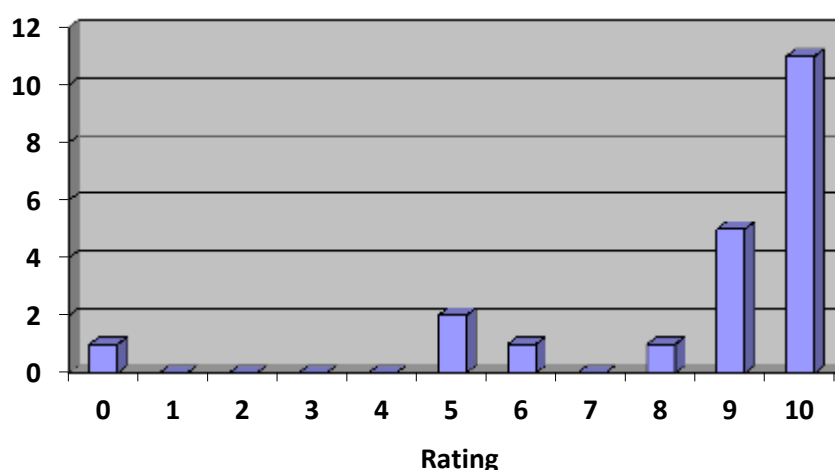
71% of the participants gave a rating suggesting the project had benefited them physically.

Appendix 7.4 – Patient evaluation survey and full responses

Comments included:

- 'More strength in legs, walking more, sleeping better and feel stronger'
- 'Makes you more active'
- 'Used my affected hand more'
- 'Getting in and out of taxis'
- 'Arm and hand function'
- 'Helped to improve hand dexterity'
- 'Helped my energy levels, felt more energy when going to sessions and definitely sleeping better'
- 'I feel I am walking so much better and want to do more now. I am also sleeping better which I feel is from relaxing me playing the music'
- 'Stamina, flexibility'
- 'My walking is much better, I still use a walking stick but I don't feel as dependent on it, my sleeping improved very much. I found after the group I would sleep very well that night'
- 'Mobility wise, I had to force myself to stand and walk and sit in my wheelchair. It forced me to get a shower! I often don't because I have to rely on someone to help me'.
- 'I suffer dizzy spells since my stroke and found these subsided when concentrating. I found the groups very relaxing'

5. The music project has benefited me emotionally (e.g. mood, confidence)



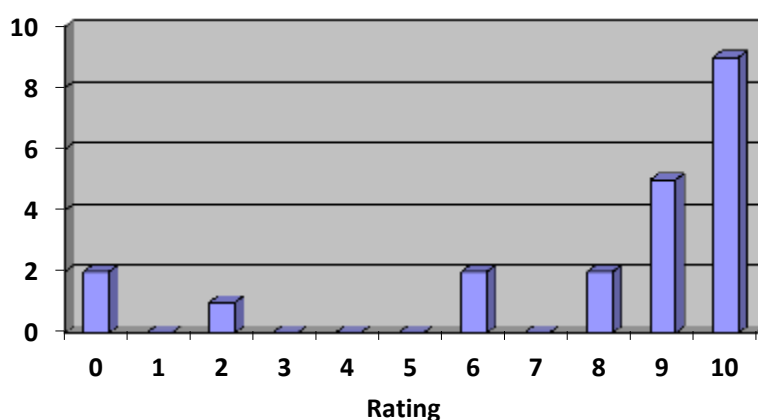
86% of participants agreed with the statement that the project benefited them emotionally, with 52% totally agreeing with this.

- 'People told me I appeared more happy; I feel more confident especially talking in a group'
- 'It's like a team effort, you're not on your own'
- 'The music group sessions lifted my mood and gave me more confidence to have a go at anything'
- 'Confidence'
- 'Helped me to "Move On", energised me'
- 'I think this project and other projects I have taken part in have made me feel better about my life ahead'
- 'Lifted my morale and mood, gave me something to look forward to'
- 'My confidence improved around a group of people and I looked forward to each session. I would panic if the taxi picking me up was late as I was eager to get there and didn't want to miss anything'

Appendix 7.4 – Patient evaluation survey and full responses

- 'I feel I have much more confidence, especially around people I don't know. Looked forward to the sessions very much'
- 'I had to get up and ready'
- 'We always leave with a smile and it helps let out emotions'
- 'Mood and confidence'
- 'My confidence improved, I found myself dressing up for the groups! I was always looking forward to them, my confidence around other people improved much'
- 'Improved my mood and confidence'
- 'Mood wise – 10; it was always calming and relaxing. There was nothing bad about it to create a bad mood. The whole aspect of it was calming. When talented people were trying to coach things out of you – like "come and join our gang" everyone saying what it had done for them at last session'

6. The music project has benefited me cognitively (e.g. attention, concentration, memory)



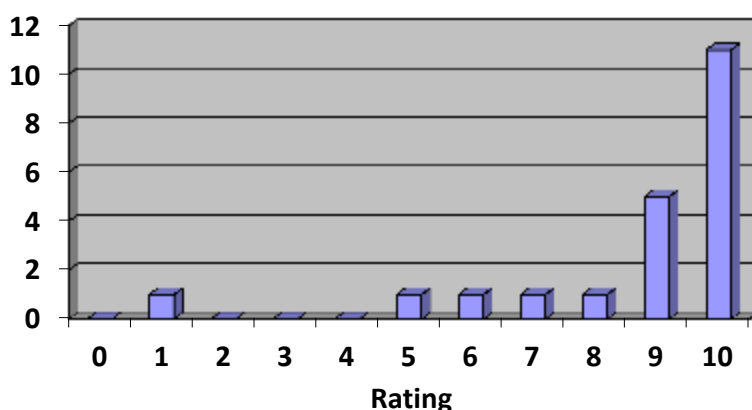
86% of participants agreed with the statement that the project benefited them cognitively, 43% totally agreed with this statement. Three people did not agree that it had benefitted them cognitively.

Comments include:

- 'Concentration improved when playing instruments, and more attention although memory still the same'
- 'It's helped with my memory'
- 'Has improved my attention and concentration and find myself interested in music more'
- 'Concentration, keep focused'
- 'Attention and memory'
- 'The project has benefitted me, but I have put 8 as even in the final concert I had difficulty keeping up with the notes required'
- 'Helped me concentrate'
- 'My attention and concentration has been much improved'
- 'My concentration is better, especially when I was playing the instruments, also listening to the musicians'
- 'You need to concentrate to do the music'
- 'I had to concentrate a lot to remember rhythm, beat and timing'
- 'When I was playing an instrument or listening to the music, I was very focused. The group has definitely improved my concentration and attention'
- 'With using the instruments such as tambourine improved my concentration'

Appendix 7.4 – Patient evaluation survey and full responses

7. The music project has benefited me socially (e.g. communication, social interaction, relationships)



91% of participants reported that the project benefitted them socially, with 52% totally agreeing with this statement. One person neither agreed nor disagreed and one disagreed with this statement.

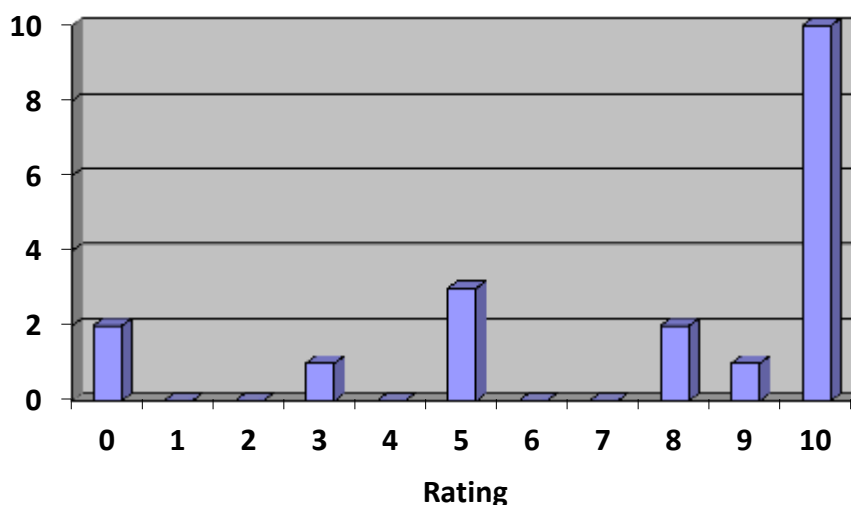
Those that agreed with this statement commented:

- 'Enjoyed the group, was fantastic, more confidence speaking in a group. Music helped me relax and not worry about my communication'
- 'Talking to other people, I like meeting people and talking. Family very busy'
- 'I enjoyed meeting other people affected by stroke and was relaxed in the sessions, giving me more confidence to talk to people I didn't know'
- 'Confidence in social interaction'
- 'Social interaction'
- 'I felt that my social interaction was fine, but I did still struggle at times and the approachability of many of the people in the project assisted me with this'
- 'Social interaction in every way'
- 'More confidence in groups. I am not one for talking a lot but the group made me more relaxed and wanting to talk to other people in the group, which I would not normally have the confidence to do'
- 'I live in sheltered accommodation and since the music group I have started to go in the common room and have coffee with others, which I never did'
- 'There were different people to speak to and they were all sociable'
- 'Working in a group brings so much positivity and enjoyment'
- 'I was part of the group, but I was also focused on what I had to do'
- 'Very much, I met some wonderful people and met people who had also had strokes which I felt some had some of the same problems as me, so I didn't feel stupid if I could not find my word when talking'
- 'Met new people'
- 'It makes you wish I could play an instrument like the others, last week I was going through it all in my mind, I had the same satisfaction I got when I built a road, when you can stand back, look and say "I've done that". Meeting the musicians – the other group members are still a bit like strangers. Musicians – there was something interesting to talk about with them'

The one person who did not agree with this statement said they 'found it difficult in large group as (I) have poor speech and (am) hard of hearing'.

Appendix 7.4 – Patient evaluation survey and full responses

8. The music project has enabled me to develop a new interest



Thirteen participants agreed that the project has enabled them to develop a new interest, with 48% totally agreeing with this. Three people disagreed and two neither agreed nor disagreed.

- 'Always loved music, more likely to listen to classical, listen for certain instruments'
- 'Definitely'
- 'Listen to music and try to pick out instruments that I can hear being played'
- 'It's made me think more about doing more mentally'
- 'Has made me think about buying an electric guitar; I played one at 18 years old, and it has fired me up to try again'
- 'I am interested in joining a music group as it's something I really enjoyed and have missed since it ended'
- 'I listen to more music, I have not listened to certain music in years, but do now'
- 'I have been trying to make my own instruments'
- 'I feel more confident about groups in general, I wouldn't normally have gone to a group as I would have been embarrassed. Would go again'

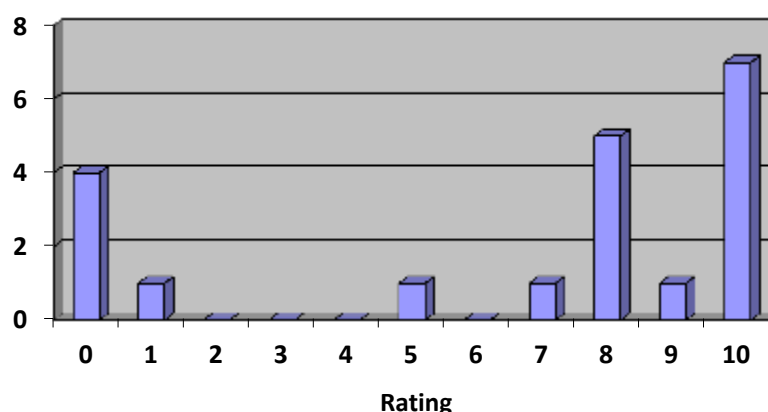
The people who neither agreed nor disagreed with the comment reported:

- 'I've always had a very varied taste in music, but it has helped me listen more and hear the music. I asked Phil if he had played with Alfie Boe and have spent about half an hour talking about it. Shaped interest rather than given a new one'
- 'I found the project interesting and helpful to me, but I am unsure whether I would now want to take part in musical activities as a long term past time'

The two people who did not agree with the statement did not make further comments.

Appendix 7.4 – Patient evaluation survey and full responses

9. The music project has enabled me to learn a new skill

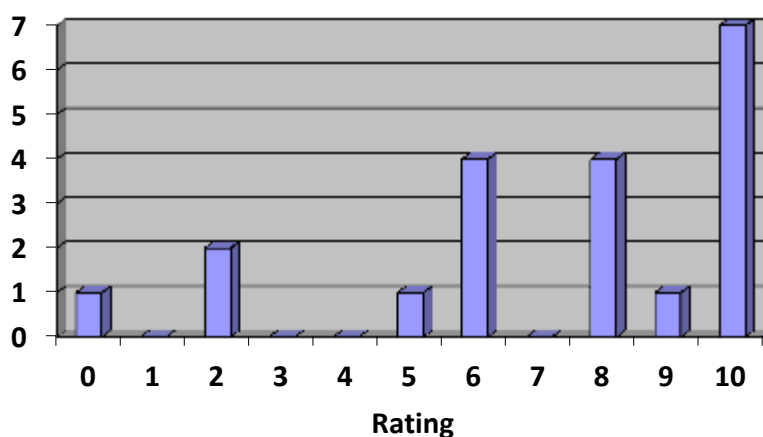


67% of the participants rated that the project had enabled them to learn a new skill, 33% totally agreed with this statement. 24% rather that they disagreed with this statement and one person neither agreed nor disagreed.

Comments made related to this statement include:

- 'Learned communication in a group, confidence improved'
- 'Tall drum-tilt on an angle so the noise comes out of the bottom'
- 'Listening to music more, meaning listening to the instruments, where as I would not have done that before'
- 'Rhythm'
- 'Play an instrument'
- 'Playing music'
- 'It has shown me how music can be made simply'
- 'I've always wanted to learn to play an instrument, especially the drums. I am not an instrument player but felt I learnt some rhythm playing the drum'
- 'I learned more about music and different instruments'
- 'Playing an instrument however simple'
- 'Drumming'
- 'I can play to a rhythm with my marracas! I can now talk in a large group setting'

10. The music project has changed the way I listen and attend to music



Appendix 7.4 – Patient evaluation survey and full responses

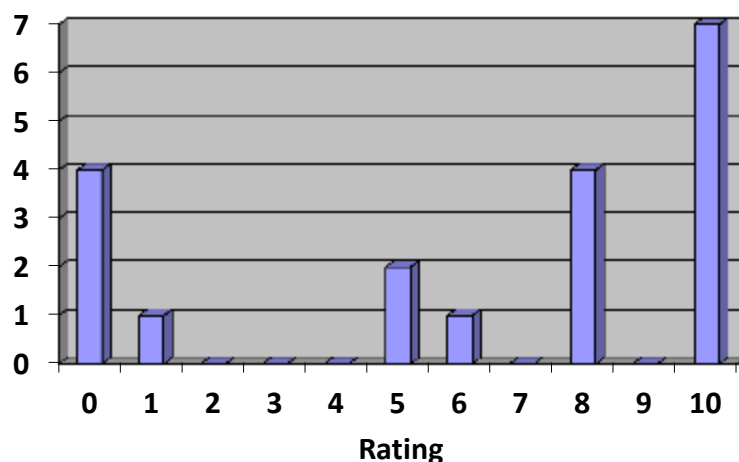
76% agreed that the project had changed the way they listen to music, with 33% totally agreeing with this statement. Three people did not agree and one neither agreed nor disagreed.

Comments included:

- ‘Listen for different instruments, concentrate more and listen to different types of music’
- ‘I have always liked music, Abba use same instruments in every song-I’ve never noticed that before’
- ‘Listen to the instruments more and try to recognise what instrument. Also introduced me to more classical music which I would not have previously listened to, also watch the conductors more’
- ‘Yes it has changed the way I listen, made me appreciate music more’
- ‘I find myself listening to the instruments playing’
- ‘Still listen to music, but more aware of the background music when I am in shops’
- ‘I take more notice of an orchestra if it comes on the TV, before I wouldn’t have been interested. I think I am more interested in orchestra music’
- ‘We hear things in the music we never heard before’
- ‘Listening to the beats and the rhythm and when I had to come in’
- ‘I’ve always enjoyed music, I listen more to symphonies, and it’s awakened my classical side. I notice music more especially when I am in shops’
- ‘I have always loved music and dancing but find I am now listening to the instruments in the music more’
- ‘When watching TV, I hear the music more in the background where as previously wouldn’t have noticed’
- ‘If I put a CD on I’m listening more intent now (e.g. Andrea Bocelli, Katherine Jenkins). Listen to the music now not just singing. It’s a good thing and educational – picking certain parts of the music out. Even if a cowboy film on, I listen to the music’

One of the participants who did not agree with this statement said they ‘have always enjoyed listening to music, and as such listened to a wide variety from classical to rock’.

11. The music project has increased the amount of time I listen/play music



57% agreed that the project has increased the amount of time they listen to or play music, 33% totally agreed with this. 24% did not agree with this and two people neither agreed nor disagreed.

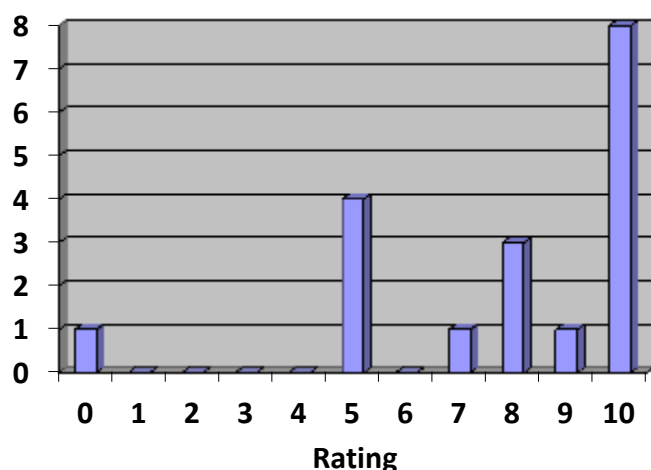
Appendix 7.4 – Patient evaluation survey and full responses

- ‘When there’s nothing on the TV’
- ‘Always have the radio on, but now listen to different sorts of music’
- ‘I love all music’
- ‘Also increased types of music I now listen to’
- ‘Always listened to music, maybe a bit more now’
- ‘If it’s on the TV I try and listen more. I am more interested, especially when I hear the French horn, I look out for that. I wasn’t familiar with a French horn before’
- ‘We have music on constantly’
- ‘I do listen to music more and I find I listen to music louder too, to see if I can recognise instruments’
- ‘Definitely increased although a difficulty getting to play it (physically)’

Those that did not agree with the statement made the following comments:

- ‘Not easy for me to put the music on independently, but I have asked my family for a little CD player so I can put it near me’
- ‘I always had music on, radio on all the time’
- No different

12. The music project has given me benefits my other therapy does not

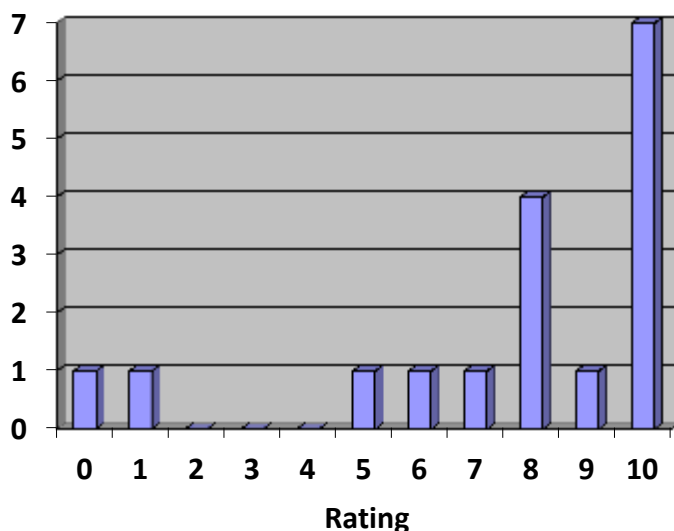


62% agreed that the project gave extra benefits compared to other forms of therapy, with 38% totally agreeing with this statement. 19% neither agreed nor disagreed and one person disagreed.

- ‘Far more informal, feeling of a common cause, able to chat’
- ‘More confidence in a group setting, helped me relax without knowing it’
- ‘It’s different and interesting. Tim brings out the best in everybody’
- ‘Going to the sessions and being in a group, I interact with people in the same situation as me and learning others experience of stroke’
- ‘Social interaction. Helped me work on finger/hand dexterity in a way I enjoyed, encouraged me to continue. I wouldn’t be using my hand like I am now’
- ‘Meeting people in the same situation as me and improving my concentration’
- ‘Gave me confidence around other people and meet with friends more’
- ‘Being out in a group and doing something totally different has helped so much’
- ‘Being a member of a group’
- ‘Being in a group setting with people I feel helped my communication and listening skills’
- ‘If it wasn’t for you I wouldn’t have gone. They both go hand in hand, it gives me the ability to go to that’

Appendix 7.4 – Patient evaluation survey and full responses

13. Engagement in the project has had a positive impact upon my symptoms during the sessions



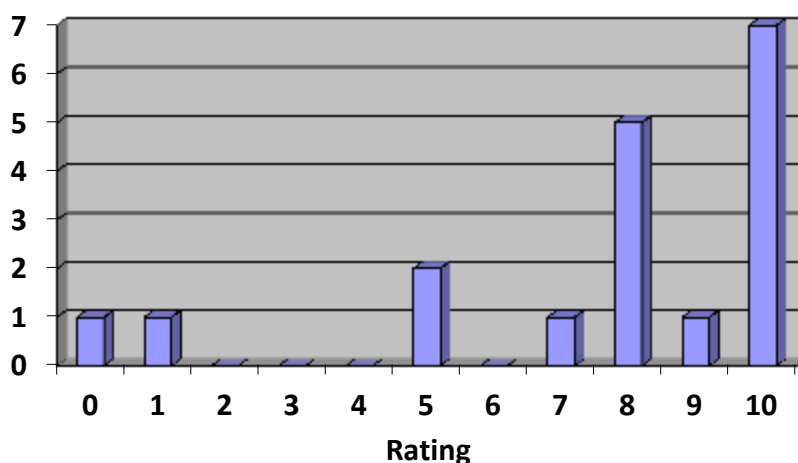
86% agreed with the statement, with 33% totally agreeing. Two people said they did not agree that the project had a positive impact on their symptoms during the sessions and one person neither agreed nor disagreed.

Comments included:

- 'Relaxed my mind more and helped with my epilepsy symptoms. Stopped me thinking about my stroke'
- 'I felt the music helped me relax which helped pain symptoms and it did not feel like therapy when playing an instrument'
- 'Helped me to forget them'
- 'The project has helped me improve my mood and concentration'
- 'I found that the dizzy spells that I suffer with went when I was at the group and concentrating on the music'
- 'More energy, more confidence'
- 'I looked forward to getting ready and doing it'
- 'You forget what you can't do and work with what you can do'
- 'Concentration'
- 'Yes, I struggle with understanding of conversations, but as the group went on I found myself understanding more, and talking more'
- 'Relieved tension/frustration'
- 'I was looking forward to the concert. It got me thinking a lot, e.g. Tim talking about the first instruments and how they developed and how developed to make weapons. Calming two hours where thoughts of ending it didn't enter my head'

Appendix 7.4 – Patient evaluation survey and full responses

14. Engagement in the project has had a positive impact upon my symptoms after the sessions



67% of the participants agreed that the project had a positive effect on their symptoms after the session. The symptoms they reported had improved include:

- 'Helped me sleep better, more relaxed, but do miss the sessions'
- 'Still listen to music and the different instruments but do miss the sessions and the interaction in a group'
- 'Feel better'
- 'Came home from session feeling I could of "ruled the world!"'
- 'Especially following the concert-on a high for a week'
- 'I feel positive about the future and things I can achieve, but feel down and low in mood when the sessions ended'
- 'Socialising in the sheltered accommodation more and go out shopping on my own'
- 'You come home and talk about it, I suppose it made me feel better'
- 'We always leave on a high'
- 'With my communication I talk more but I do miss the group'
- 'Made me aware of the need for rest as got very tired'
- Slept better

15. What did you enjoy most about the project?

When asked what they enjoyed most about the project, many participants commented on the social aspect of the group; working as a team; trying something new; and the final product of the project (both the music created and the final performance). Comments include:

- 'The companionship'
- 'Just being there as a social thing'
- 'Music, togetherness, like a jig-saw puzzle all coming together, and the end result perfect!'
- 'I liked going out in the taxi, I enjoyed seeing people, people that I knew. I lost my confidence after a fall-now much better'
- 'Meeting other stroke survivors and playing music'
- 'I love the conducting and beating the drum. Was lovely to be part of a group and to work well as a team'
- 'Everything'
- 'All of it'
- 'When everyone was playing together and hearing all the different sounds. Enjoying seeing the others smiling and enjoying themselves'
- 'I enjoyed being able to work as a team to produce music, I also enjoyed the support/help of the therapy staff in relation to the use of my left arm'

Appendix 7.4 – Patient evaluation survey and full responses

- ‘Everything’
- ‘Having something to look forward to and meeting other people’
- ‘Soothing and relaxing, meeting others who has suffered strokes’
- ‘Somewhere to go-when you get there it was sociable and everyone talks to you’
- ‘The whole experience has been amazing’
- ‘The group effect and production, the effect you get from the group, the song itself and the different pieces played’
- ‘Socialising with other people/staff’
- ‘Meeting Tim from the RPO’
- ‘The people, camaraderie, felt among friends’
- ‘Meeting with people, doing something completely alien to me’

16. What did you enjoy least about the project?

When asked what they liked least about the project, many (62%) reported that there was ‘nothing’ or did not identify anything. Of those that did comment, four of the eight people commented on the travel to and from the group, saying the taxis were often late or did not turn up.

The other comments included:

- ‘I Couldn’t see and hear everything’
- ‘I didn’t really know where the toilets where at first’
- ‘Conducting’
- ‘Being knackered at the end of the session’

17. What has been the most useful part of the project?

- ‘Meeting other people who have had a stroke’
- ‘All therapists and patients coming together’
- ‘Helped with my speech and mood, grown my confidence’
- ‘Social aspect, all useful in one way or another’
- ‘Change of scenery and something I would not have usually been interested in, opened up my music interest again’
- ‘Increased confidence when speaking in a group’
- ‘Meeting other stroke patients’
- ‘It has enabled me to use my affected hand with assistance’
- ‘Being part of the group and belonging to something’
- ‘The need to concentrate’
- ‘Working on hand, mood and concentration’
- ‘Has given me an interest in something and re-opened my music interest’
- ‘Joining in with the group and getting my confidence back’
- ‘It has been useful and so uplifting, making me feel good and wanting to learn to play and read music’
- ‘Being able to produce something at the end of it. It’s useful to have achieved what I went for’
- ‘Boosting confidence with speech’
- ‘Improving my communication, I talk all the time now’
- ‘Helping to realise that I fatigue quickly and required rest’
- ‘Getting me to start thinking of other things, something I would never have thought. Stopped my brain lying dormant and forced me to think about different areas. After 1st stroke in 1990 I got myself back into maths to use my brain (e.g. trigonometry), I suppose music has replaced the maths’

Appendix 7.4 – Patient evaluation survey and full responses

18. What has been the least useful part of the project?

When asked what the least useful part of the project was, most people said ‘nothing’. Two people commented that the project not being able to continue was the least useful part.

19. Any additional comments?

- ‘It was good to be a part of a group with a common cause’
- ‘Fantastic, immense, amazing, really enjoyed the experience’
- ‘Would love to do it again’
- ‘Would love the group to continue, have loved every minute and want to thank the staff and the RPO for their time spent with us, the whole experience was excellent’
- ‘On the 25th June I joined the RPO session at Hull City Hall. I was very apprehensive, after this first session I felt very much better. The orchestra members were very helpful and Tim was informative about how the orchestra worked and how to use the instruments. The humour and banter was infectious and friendships have developed. In all a great time was had and I hope it can continue’
- ‘Stroke orchestra-I love it, it’s just fantastic. Honestly, I loved it’
- ‘Just fab all the way through!’
- ‘When will it start again? And if not this something similar’
- ‘Since the sessions ended I have missed them a lot and would be interested if it ever starts again’
- ‘Very enjoyable, looked forward to the sessions’
- ‘I hope this will keep going forever and other people get as much enjoyment out of it as I have. This has been one of the best things we have ever done. All the staff have made this such a positive and enjoyable thing. We thank everyone so much’
- ‘I thoroughly enjoyed it, I feel lost now without the music group. Everyone was lovely and worked hard. I do miss it’

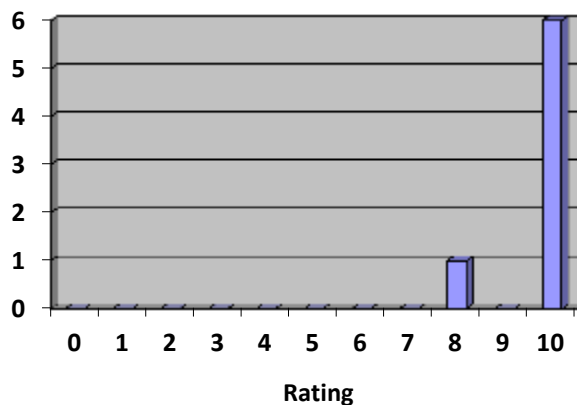
Appendix 7.5 – Carer evaluation survey and full responses



Carer evaluation survey

Carers rated on a scale of 0-10 the degree to which they agreed or disagreed with the following statements (where 0 = do not agree at all; 5 = neither agree nor disagree and 10 = totally agree).

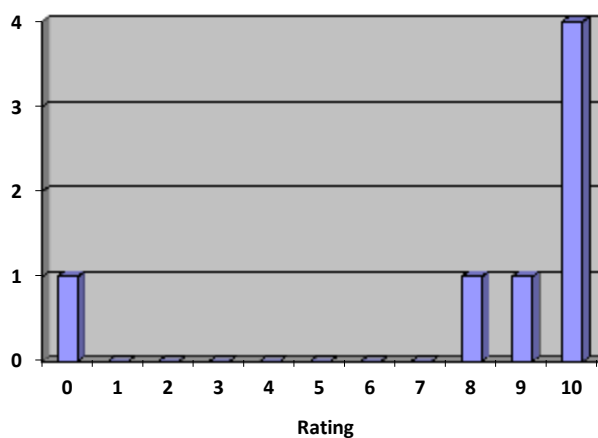
1. I have found the music project enjoyable



All of the seven carers that attended the project reported that they found it enjoyable, with 6 rating this 10 and one person rated this 8.

- Enjoyable for everyone
- Very enjoyable, something to look forward to each week in a different environment
- It was an escape from reality. A chance to escape, I got completely absorbed in it.
- The whole experience, mixing with others in a similar position, all of it

2. The music project has enabled me to develop a new interest

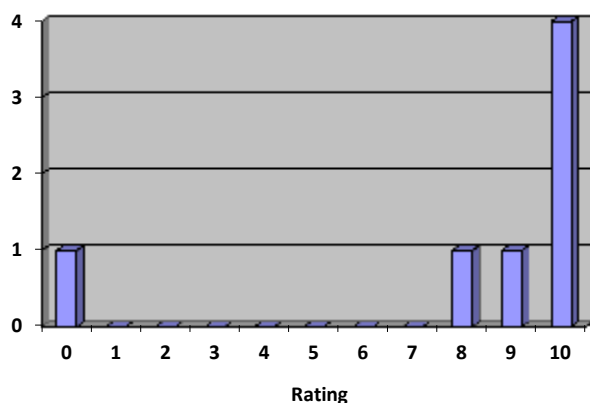


Six of the seven carers agreed that the project has enabled them to develop a new interest. Comments they made include:

Appendix 7.5 – Carer evaluation survey and full responses

- Listening to more music and taking up the keyboard more
- I have always enjoyed music
- Listen more in detail to all music
- I bought a clarinet. I can play up to 5 notes, but haven't had time to use it in the last two weeks. I desire to play it and it gave me the confidence and the assistance I had from Fraser was immeasurable.
- I want to learn how to play a musical instrument. I was looking yesterday; I want to learn how to play the flute. I have also been looking for classes and societies

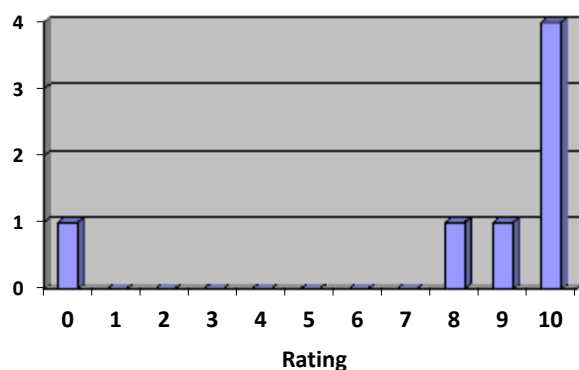
3. The music project has enabled me to learn a new skill



Six of the seven carers agreed that the project has enabled them to learn a new skill. Comments they made include:

- More interested in all music
- I have never picked a flute up in my life before. I learnt to play the flute in 3 days and I learnt my notes. I googled it when I got home "how to play the flute", so it didn't stop there. I was buzzing! I revisited my childhood; I was back in my school band playing the recorder.
- Not be afraid of musical instruments

4. The music project has changed the way I listen and attend to music

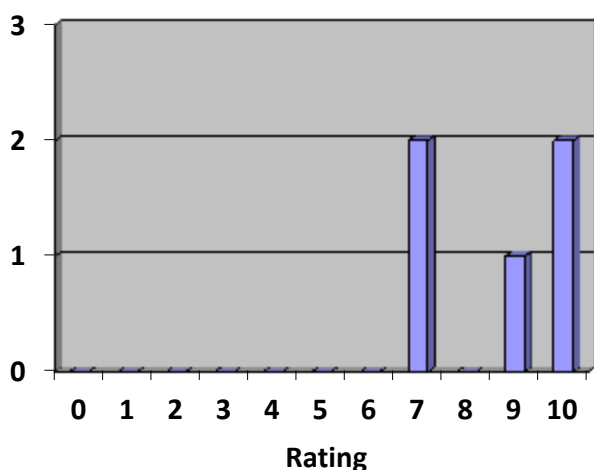


Six of seven carers agreed the project has changed the way they listen and attend to music. Comments were:

- Relate differently to different types of music
- Yes. I find myself listening with a more critical ear now, even music I've always listened to. I'm hearing things I haven't heard before, e.g. specific instruments I can pick out
- I am looking for different sounds. I think how much most have gone into it, putting together and composing it, how much most have gone into it. I have always took notice of music

Appendix 7.5 – Carer evaluation survey and full responses

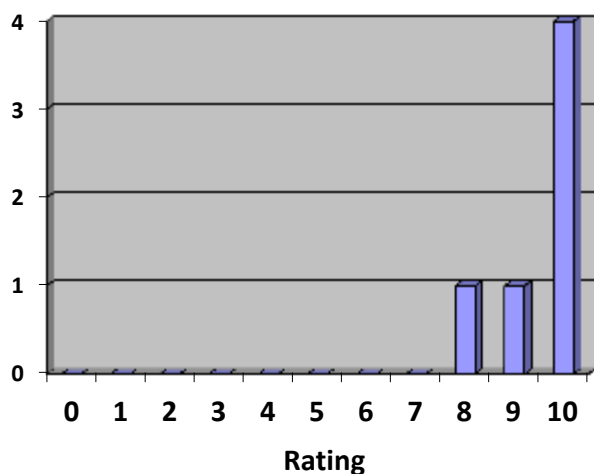
5. The music project has increased the amount of time I listen/play music



All carers said the project has increased the amount of time they listen to or play music.

- Yes, listen to more music and play more
- Listen to more music
- Due to an emotional time in my life I stopped listening to music. I found myself listening to music after the performance in the early hours
- I haven't got the time to devote more time to listening to it

6. The music project has given me respite from my normal role as a carer

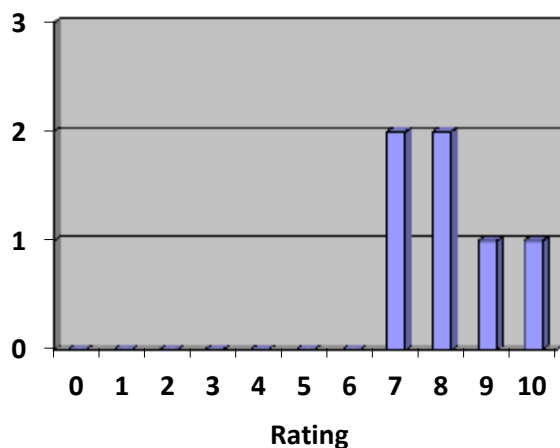


All carers said that the project gave them respite from their role as a carer:

- Yes, it was good to get away from everyday housework/carer role, something to look forward to.
- Time to relax
- A breath of fresh air
- I loved those two hours of being detached from my partner and let him do his own thing and I do my thing, allow me to be myself and socialise with everyone. Respite. Seeing my partner enjoy himself and I wasn't worrying about him
- It enabled me and my mind to get away from the daily routine

Appendix 7.5 – Carer evaluation survey and full responses

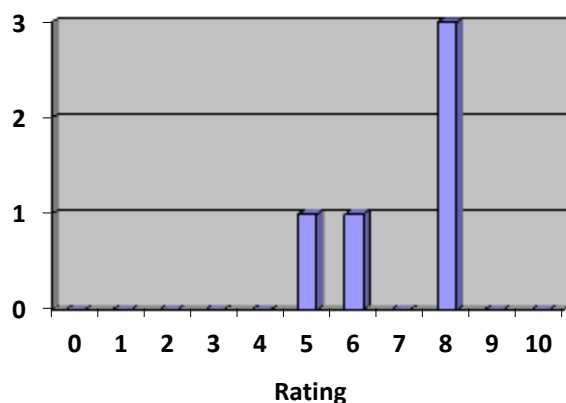
7. The music project has benefited my personal wellbeing (e.g. mood, motivation, engagement)



All carers agreed that the project had benefited their personal wellbeing. Comments made regarding this include:

- Lightens your mood
- My husband being relaxed helps me relax
- A release from the norm
- My lifestyle at the moment doesn't allow the full benefit i.e. playing the clarinet and listening to more music. Not enough time
- It has motivated me to look at what is going on out there as far as hobbies; interests. It has opened my eyes. It's given me a bit of confidence...found my confidence again. I'd forgotten what a bubbly outgoing person I had forgotten who I was.
- Loved being part of something bigger

8. I have noticed a physical improvement in my patient (e.g. mobility, energy, arm function, sleep)

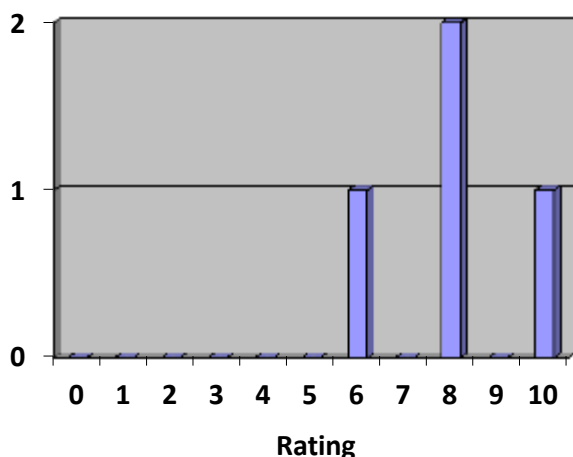


Four of the carers agreed that they noticed physical improvement in the individual. One carer rated this as 5 (neither agree nor disagree) and two responded that this was not applicable.

- Yes, as he has something to look forward to
- Takes his mind off his stroke problems
- Definitely had more energy, he was more relaxed. He definitely started using his arm more. E.g. he started using it when doing the washing
- I noticed improvement with something; it was thrilling for me to see her remember what instrument and how to play it. She even remembered which parts of it to hit.

Appendix 7.5 – Carer evaluation survey and full responses

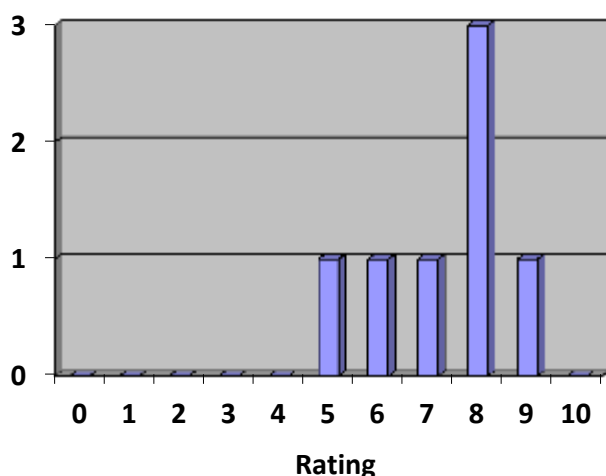
9. I have noticed an emotional improvement in my patient (e.g. mood, confidence)



All carers reported they agreed with the statement that there had been an emotional improvement with their relative there had been an emotional improvement with their relative.

- Yes, he is more happy on the day we have therapy
- Gives my husband more confidence in everyday duties
- It was the first time he was motivated, it was the first time he had socialised and it was the first time he wanted to do something after- we went out for tea. I think he put his embarrassment to one side. It was the first time I saw him smile in 3 months!
- I can't say it was long lasting, but definitely at the time. She did get tired but definitely an improvement in mood

10. I have noticed a cognitive improvement in my patient (e.g. attention, concentration, memory)



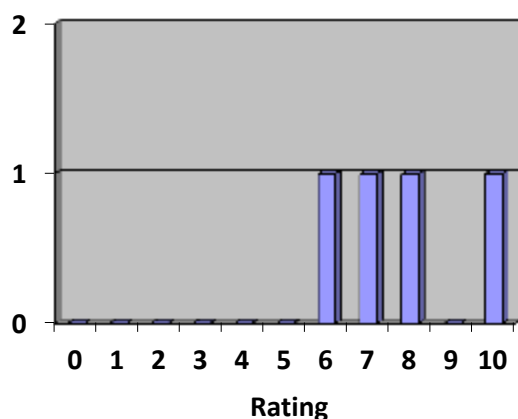
One carer reported that they neither agreed nor disagreed that there had been a cognitive improvement in their relative. The rest of the carers agreed that there had been a cognitive improvement.

- My mum's attention, concentration and memory have steadily been improving since discharge from Rossmore
- More aware and can focus on different things
- Concentrates more

Appendix 7.5 – Carer evaluation survey and full responses

- Speech improved, his attention was much better and memory-when he was in hospital I made changes to the house and he never noticed, after the project he noticed more
- Yes in the time and that context but not long lasting
- More focused, slight memory improvement

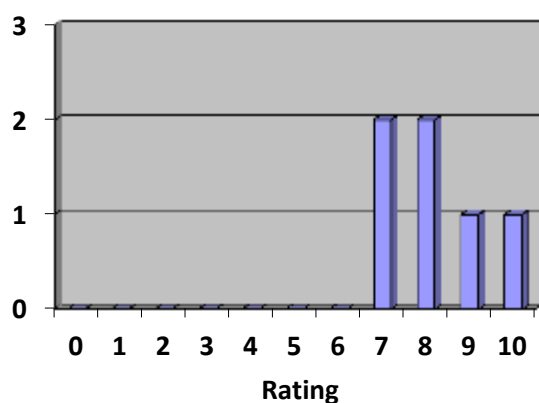
11. I have noticed a social improvement in my patient (e.g. communication, social interaction)



All carers agreed they noticed a social improvement for the individual. Comments made regarding this include:

- We both like to get out more and meet people
- My mum has always been gregarious
- My husband had become more sociable since mixing with people in the same situation as himself
- Feels more comfortable
- For me – I was really nervous when I first went, but soon felt part of a group and seeing some of the difficulties some people had made me feel, lucky and seeing them be creative and play in any way they can was good to see.
- It was good for her to socialise, she has always been a people person
- Speech improved. He started to speak on the phone e.g. boss frequently rang I always talked after the project Rich started to have more input and speak on the phone
- More willing to engage with others

12. The music project has benefitted my relationship with my patient

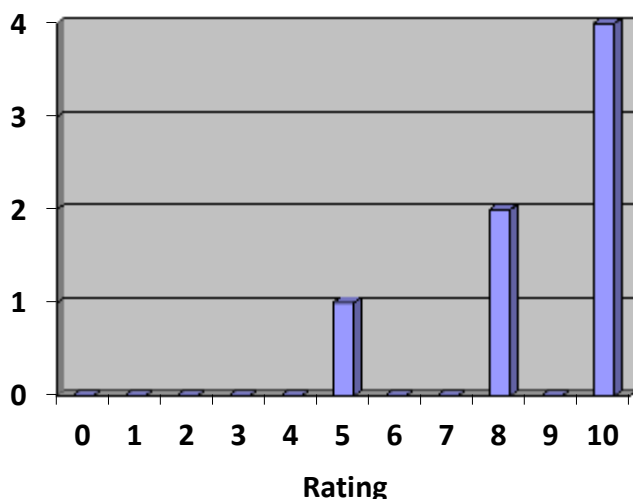


All carers responded that the project had benefitted their relationships. Comments include:

Appendix 7.5 – Carer evaluation survey and full responses

- We listen to music a lot more
- I am more relaxed when my husband is relaxed
- It was like courting all over again. I am telling him and communicating better with him even if it's in a bad way. I have started to realise he is still my partner...take that stroke bit away
- No, our relationship couldn't be improved!
- It was a positive experience, something different and got Elsie into a new experience. That was the biggest experience. At first I thought 'what have I got into' and worried about the performance but I really enjoyed it. The compact venue helped
- We shared the same nerves! i.e. the night at Hull city Hall

13. The music project has given me and my patient benefits other therapy does not



- Meeting other people in the same situation, knowing you are not alone
- It is therapy that you can do together; both get involved in on an equal level. It knocks down all the boundaries, therapists and patients are all equal, the professional boundary wasn't there, it allowed the therapist to see a person rather than a person who had had a stroke, and the patient see them as an equal. With other therapy you have a teacher and a doer.
- It was an experience we couldn't have had any other way. Chatting to professional musicians informally and playing alongside them was great. They all helped.
- Not sure about this yet as we have nothing much to compare, but this therapy was special

14. What did you enjoy most about the project?

- Everything
- To see my mum enjoying the company of others
- The way everybody interacted with each other
- The whole experience has had such a positive effect on us both
- The social aspect
- The final performance
- Mixing with other people, doing a similar thing
- Meeting other carers and people who have suffered strokes. Meeting members of the RPO and creating music that connected us all and speak for us all

Appendix 7.5 – Carer evaluation survey and full responses

15. What did you enjoy least about the project?

- I had an active role in the project but hated it if the spotlight was turned on me
- Coming home
- Nothing
- The length of the final day. My patient found it very tiring even though they loved the whole day

16. What has been the most useful part of the project for your patient's recovery?

- All of the therapy
- Getting out and meeting and making friends with people who have gone through the same as ourselves
- Gave him some confidence and a sense of achievement and purpose
- The ability to socialise with a different group of people I regard it as a privilege to mix with a group of individuals in a similar position to ourselves in this.
- It made me feel I wasn't the only one in my position. Caring can be a lonely path at times and you can feel sad.
- The social side of it and helping with concentration

17. What has been the least useful part of the project for your patient's recovery?

- Nothing, everything was so enjoyable
- Nothing
- N/A
- The waiting for taxis, which could sometimes be stressful

18. Any additional comments/suggestions?

- All good it would be nice to start again
- I hope you can carry on with your good work as it is a benefit to anyone in the same situation as ourselves
- Without this project I believe we would not be as far on as we are now. We have loved the whole thing.
- It was just brilliant really, it was enjoyable, life changing, I rediscovered myself again. There is more to life than you realise and there is a life after all this and there are areas of interest to explore
- I'm glad it will continue in some form or another and feel good someone wants us to play again!
- The musicians were marvellous. The improvisation was amazing
- Tim was great it need Tim to continue
- It was brilliant really!
- It was enjoyable; life changing... as I rediscovered myself again. There is more to life that you realise and thee is a life after all this and there are areas of interest to explore
- Let's make more music, cut CD's and sell them for charity

Appendix 7.6 – HICSS staff evaluation survey and full responses



Royal Philharmonic Orchestra

HICSS staff evaluation survey

All participating HICSS staff were asked to complete an online questionnaire about the project.

1. Did the project meet your expectations?

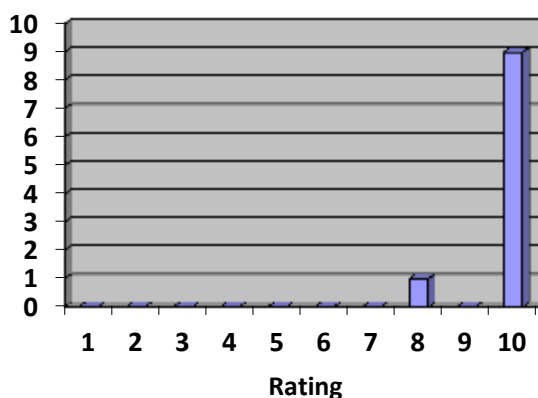
- a. Yes: 10; 100%
- b. No: 0; 0%

If no, what did not meet your expectations?

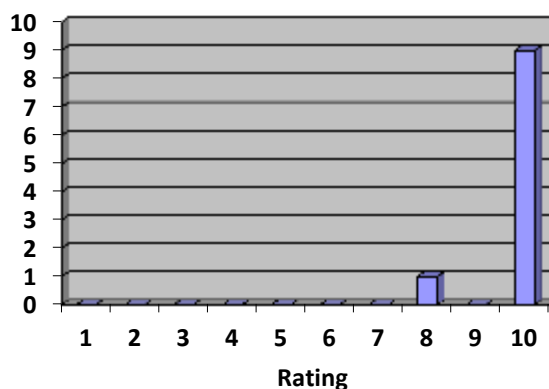
- It wasn't like anything I was expecting. I didn't expect to enjoy it as much as I did.

2. On a scale of 1-10 where 1=not at all successful and 10=absolutely successful, how would you rate the following aspects of the project?

a. RPO musician engagement with patients

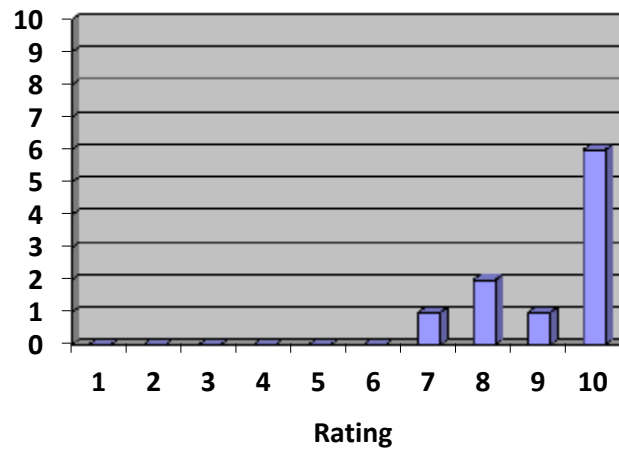


b. Creative leader engagement with patients

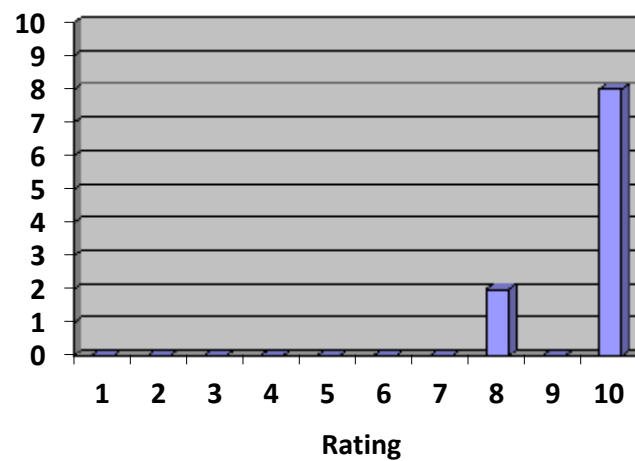


Appendix 7.6 – HICSS staff evaluation survey and full responses

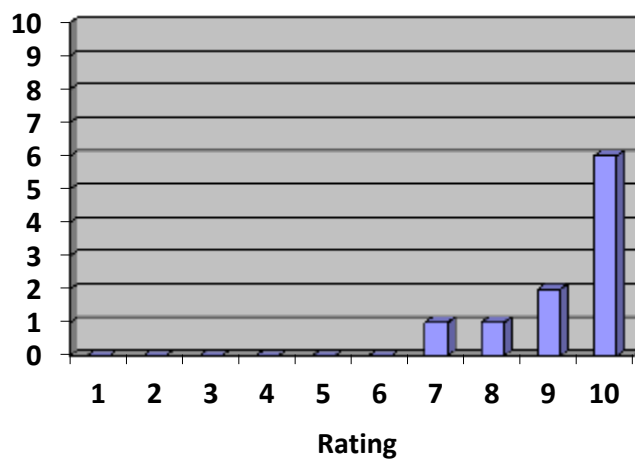
c. Creative team understanding of patient needs



d. Creation of a supportive group environment for patients

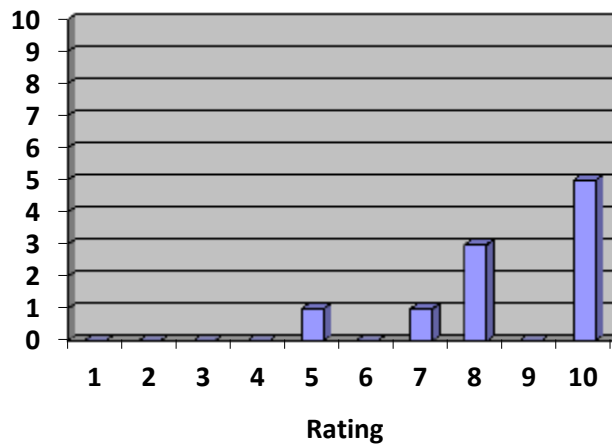


e. Creation of a supportive environment for HICSS staff

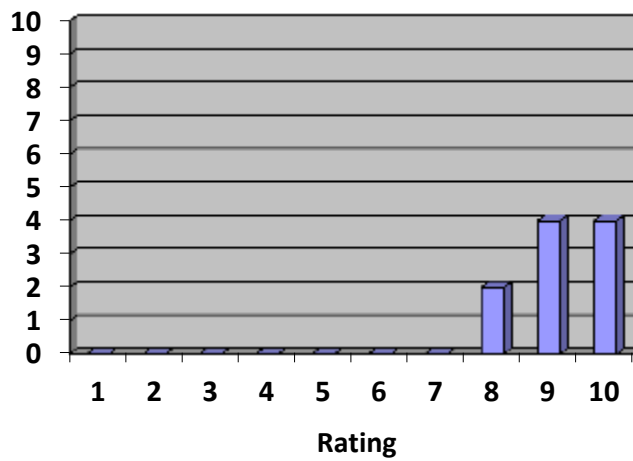


Appendix 7.6 – HICSS staff evaluation survey and full responses

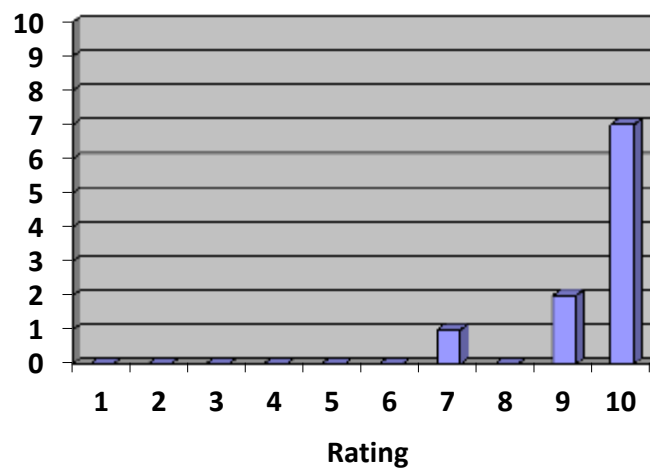
f. Opportunities for work supporting physical goals



g. Opportunities for work supporting cognitive goals

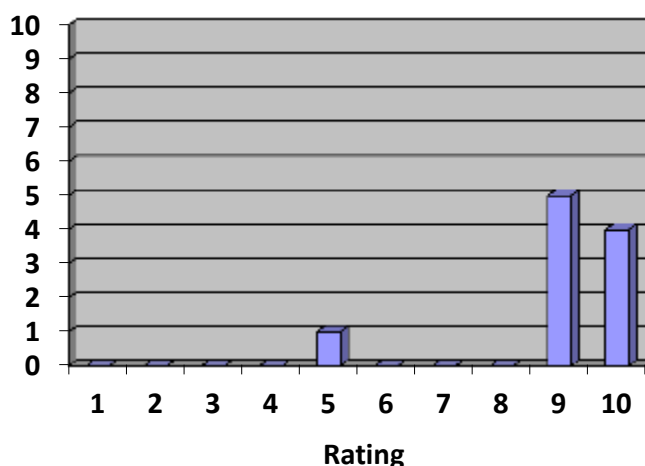


h. Opportunities for work supporting social goals



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i. Opportunities for work supporting communication goals



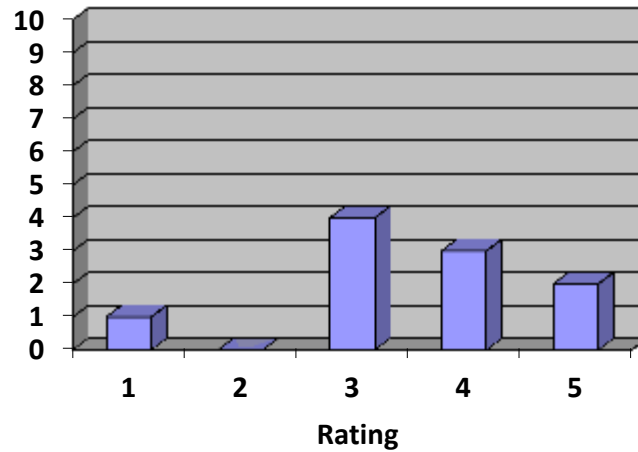
Please clarify with additional comments as necessary:

- Work did support physical and other goals, however, at times the creation of music overshadowed this, but perhaps through the creation of music it also maintained engagement in activity, therefore has possibly prolonged therapy or re-ignited enthusiasm.
- I have thoroughly enjoyed all aspects of the project and in particular our joint learning. The project has enabled us as clinicians to learn musical skills and techniques which we can apply to a multitude of impairments and it has been a great pleasure to share our clinical knowledge and experience with interested, enthusiastic and incredibly talented musicians.
- I found this project inspiring and energising. It has re-ignited my own personal interest in music, which has helped my wellbeing, health and ultimately my work. It has made me re-evaluate how we work with patients and the priorities we have and if we need to revisit these. physical goals - I found that the patients were often very focused on joining in and being successful in the music and therefore would rather focus on creating the music than using affected limb, standing etc. however, their confidence did improve. I think it helped with things like tone and pain, but also generally with body image and accepting of their disabilities which meant that they were more able to work on their therapy outside of the group.
- The project benefitted all of the patients that went, not only with socialising and communicating in a group but been able to focus on their own individual needs, whether that need was communication, cognitive or physical.

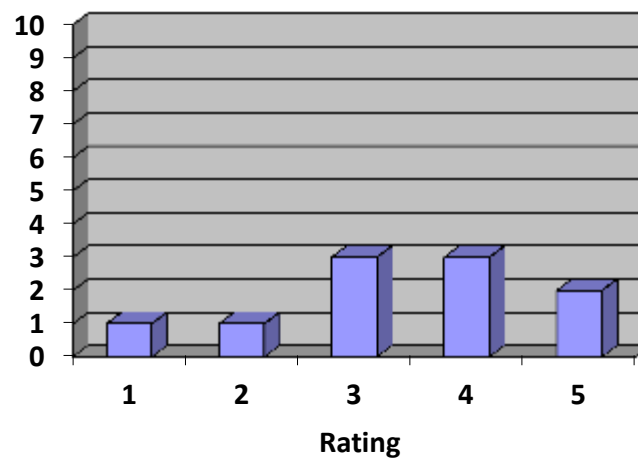
Appendix 7.6 – HICSS staff evaluation survey and full responses

3. Before taking part in the project, how confident were you that the project would achieve the following results? Please rate each aspect on a scale of 1-5 where 1=not at all confident and 5=absolutely confident.

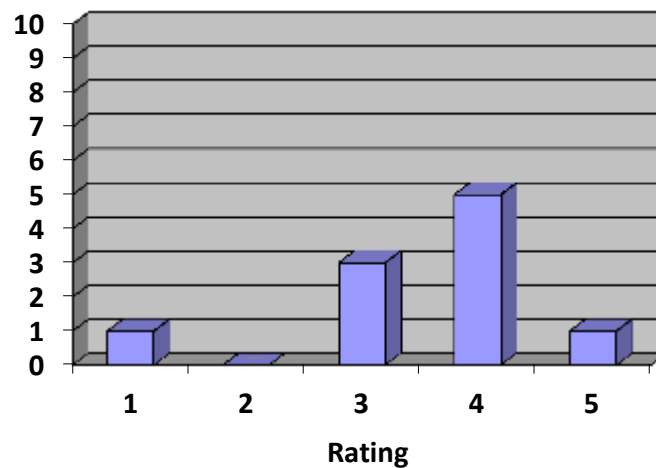
a. Give patients enjoyment



b. Assist with patients' physical recovery goals

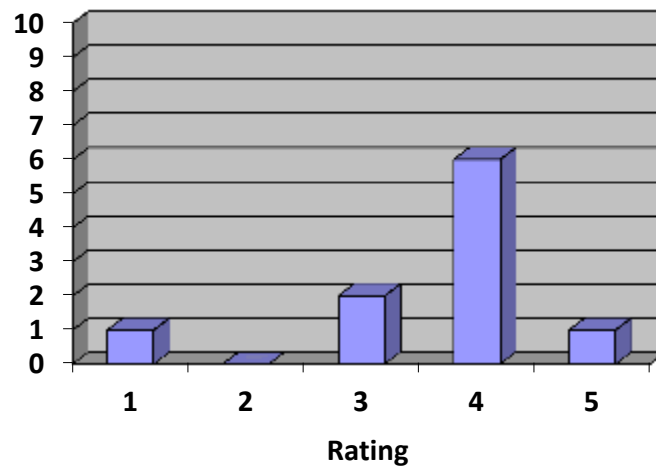


c. Assist with patients' cognitive recovery goals

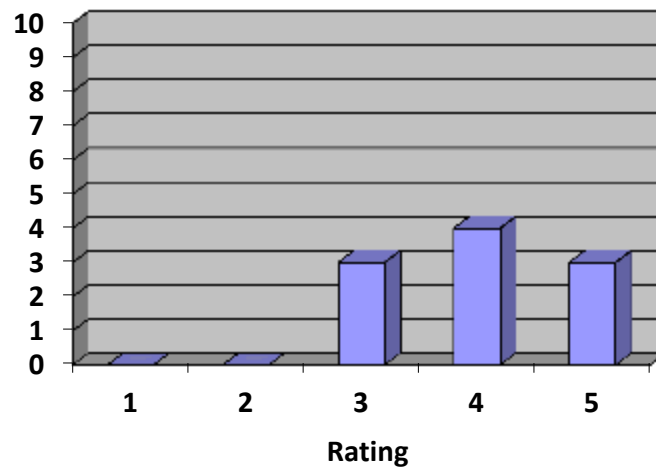


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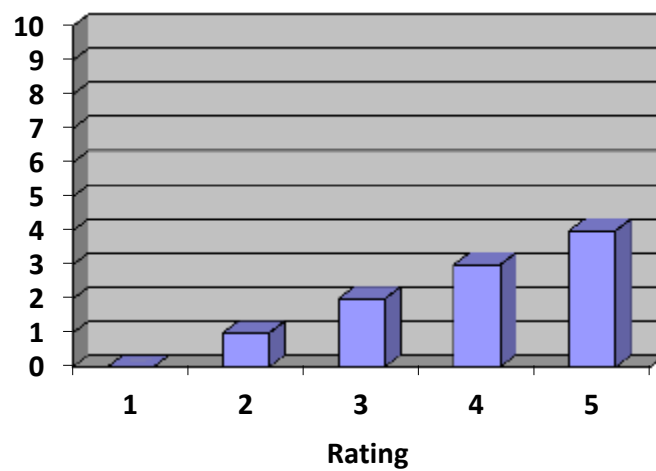
d. Assist with patients' communication recovery goals



e. Assist with patients' social recovery goals

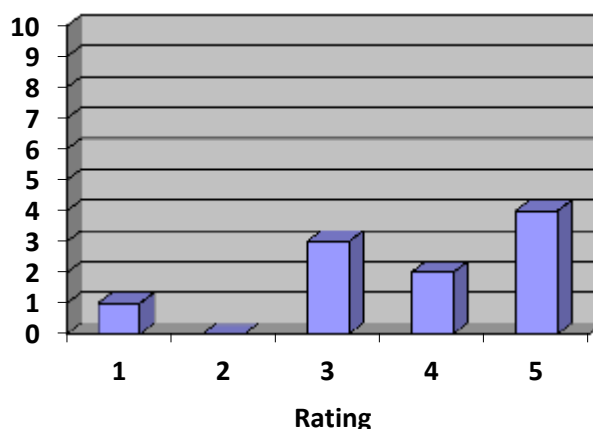


f. Improve patient wellbeing

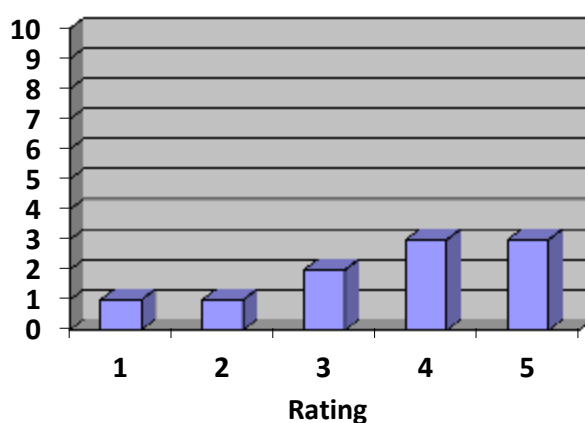


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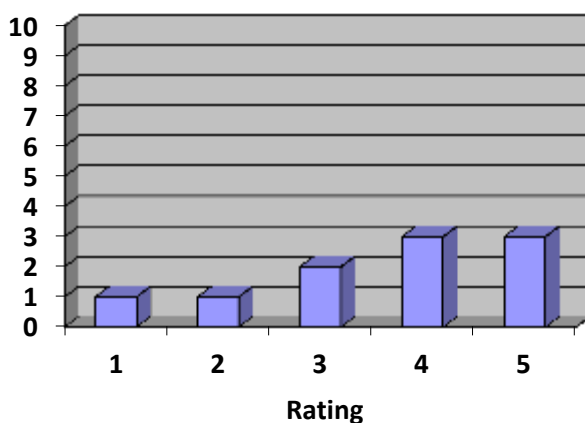
g. Provide respite for carers



h. Improve relationships between carers and patients



i. Improve staff morale



Please clarify with additional comments as necessary

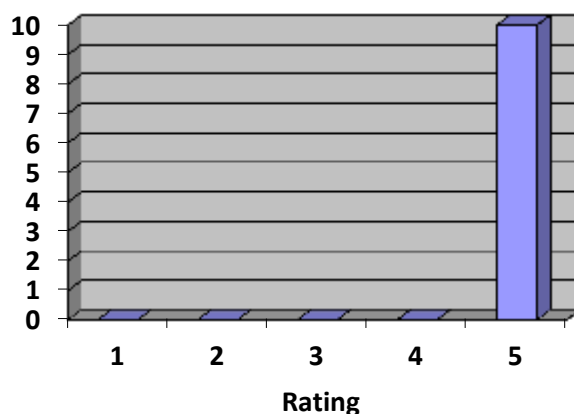
- There are some patients who have not wanted to participate in this.
- The evidence base suggested it could do all of the above but seeing is believing. There was initial apprehension in the team from some members so I did not realise the potential benefit to staff morale in the early preparation stages.

Appendix 7.6 – HICSS staff evaluation survey and full responses

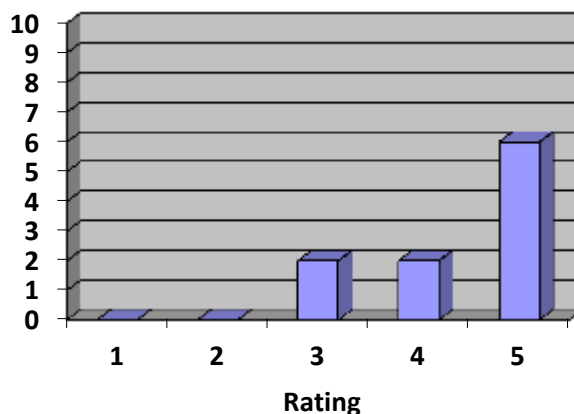
- I consulted the evidence base and it suggested that most of the above could be attained, however I was not absolutely confident until we had got going with it and experienced the positive impact. I do feel there was some uncertainty from a lot of the team in the early stages and this did add to apprehension with regard to staff morale. As the project got going and gathered momentum and the involved staff realised the positive effect within both process and product of the group I feel it had a huge benefit to staff morale and sometimes in those who were perhaps the most cynical to start. It was such a pleasure to see both patient and staff mutually benefit being involved in something new, innovative and fun but also very therapeutic.
- I did not feel we had enough time. When I have done groups before they have taken so much time to organise that it was so stressful it wasn't useful. Also, in order to meaningfully work on physical and cognitive goals you still need one-to-one support so I couldn't see how this would be any better than individual therapy
- I had done nothing like this before was unable to know what would be achieved.

4. Following the project, how confident are you that the project achieved the following results? Please rate each aspect on a scale of 1-5 where 1=not at all confident and 5=absolutely confident.

a. Give patients enjoyment

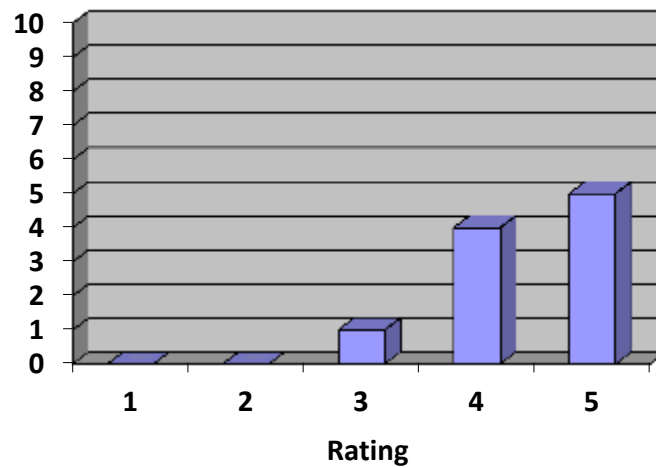


b. Assist with patients' physical recovery goals

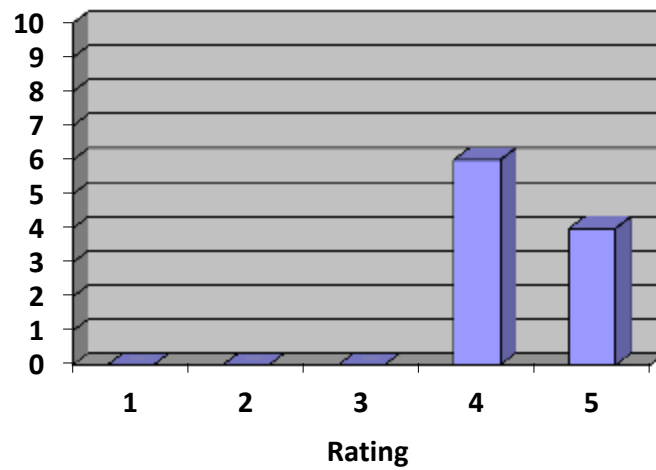


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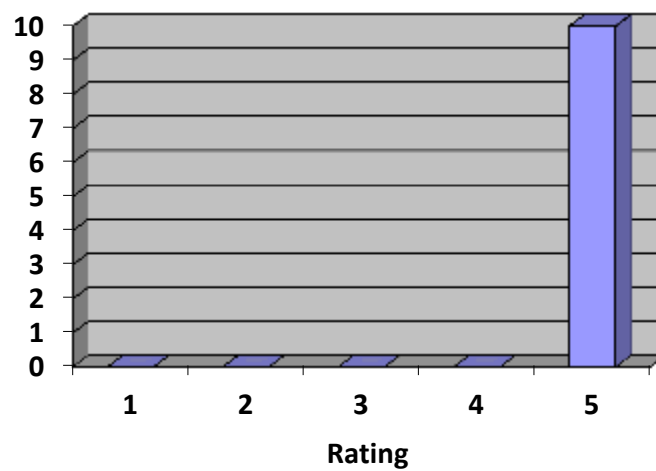
c. Assist with patients' cognitive recovery goals



d. Assist with patients' communication recovery goals

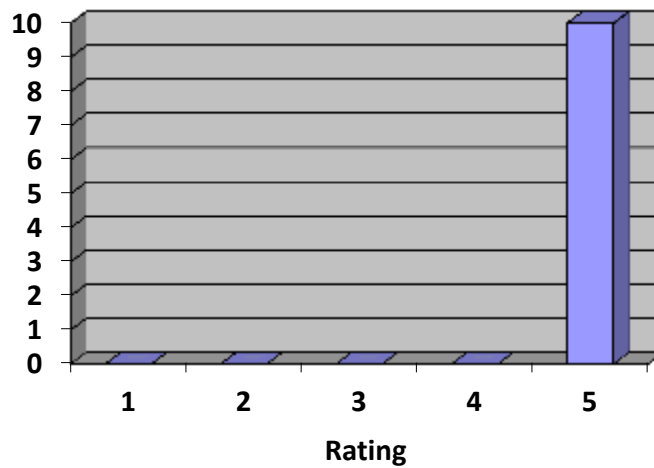


e. Assist with patients' social recovery goals

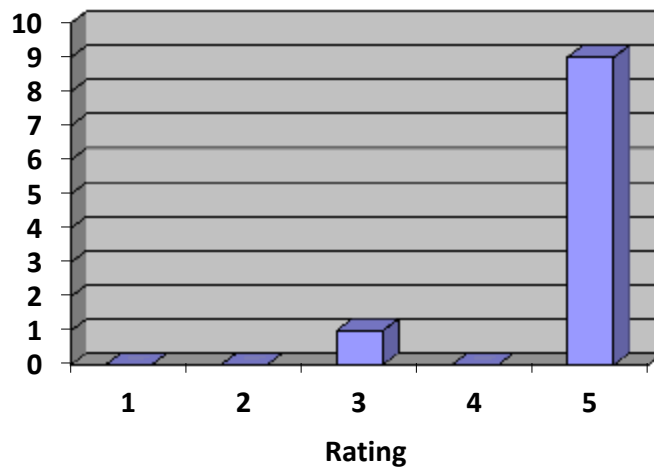


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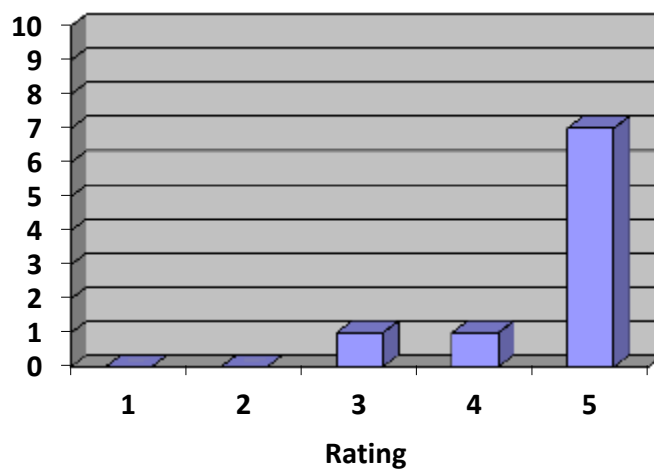
f. Improve patient wellbeing



g. Provide respite for carers

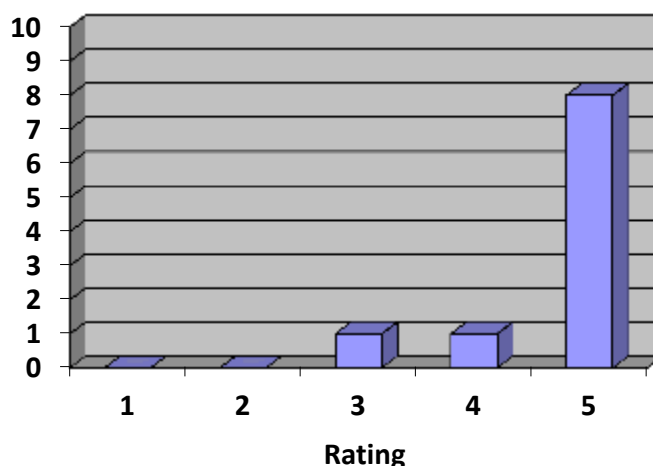


h. Improve relationships between carers and patients

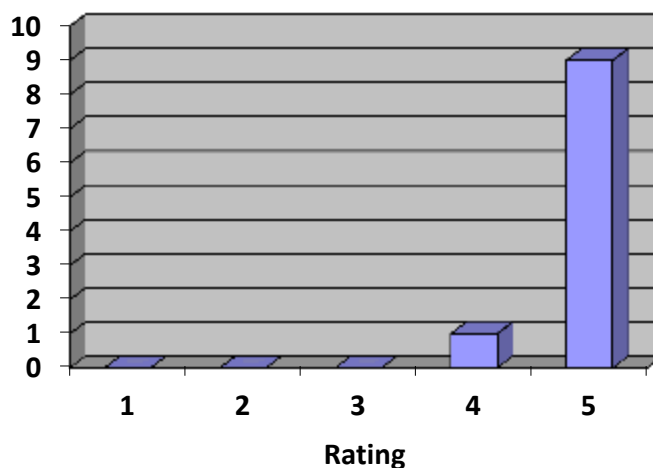


Appendix 7.6 – HICSS staff evaluation survey and full responses

i. Improve relationships between patients and staff



j. Improve staff morale



Please clarify with additional comments as necessary.

- Patients obviously gained enjoyment, improved in confidence and in some cases blossomed socially. Staff were pleased with achievements, however, the extent of input required was stressful.
- It was great to see attitudes of staff and patients change as they gained confidence and experienced the positive energy within the group.
- Each of the patients/carers I referred into the project benefited in many areas and everyone develop in confidence and enthusiasm was fantastic and energising.
- The amount of time and intensity of staff time was just as much as individual therapy. However, the opportunity for rehabilitation in this group setting, the amount of demand on all brain skills was inordinately more than we could provide in one-to-one sessions in a person's home. For me it provided the opportunity for people to realise they can do things, go places and achieve just as they did before their stroke when given support to manage the effects of their disabilities. This is something that is VERY difficult to do for people who aren't going to do this anyway. It has completely transformed my understanding of what group therapy can provide. Groups have previously been sold as cost effective way of

Appendix 7.6 – HICSS staff evaluation survey and full responses

providing therapy (ie. reduce travelling time and seeing more than one person at a time). This is not the case. However, I believe the effectiveness of the therapy was 10 fold and outweighed the amount of time required which in turn made it cost effective.

- I was under the impression from the start of how wonderful this opportunity would be for patients and staff too. Music in general helps with relaxing people, helping them forget their worries, and been able to join in with creating the music could only benefit them physically too.

5. Which aspect(s) of the project did you find most useful for working towards patient goals?

- The whole Orchestra team were very engaged and Tim very skilled in starting at an appropriate level and gradually building activity - because of this, it was easy to weave a patient goal into the activity - either through positioning or use of a particular technique etc.
- There was so much potential to work on all impairments and towards all goals. For me there was something very special and powerful about using music as the medium for group therapy which you cannot get from other mediums. I can acknowledge that other mediums may also give benefits that the music does not give but I think there is something very powerful about the immediate connection with other group members e.g. you hit a drum and there is immediate feedback in the context of everyone else's so there is that interconnectedness and you playing a part in that which is hidden and hard to articulate but I feel very empowering for a lot of people. Having to keep track of a rhythm and or contribute to the rhythm can have huge benefits to neuroplasticity according to the research and I did observe peoples increased energy and at times movement and confidence with standing and mobility. Whilst people are having to keep track and contribute and concentrate it helps keep them absolutely in that moment and therefore all of the potential mindfulness benefits are applicable i.e. not ruminating and not worrying. In conjunction with this after the sessions it also gave people something to aim for but for those who practiced or increased their music listening away from the sessions - it had the potential to open their minds to other positive thoughts in that moment and also potential for their engagement in other activities, interests, development of skills, joining groups etc. ... I do feel overall it was enormously beneficial for mental health and wellbeing and helped all of those goals related to this as well as social integration. I also feel there was huge potential for working on goals around concentration and mental and physical tolerance.
- I feel there is something very special and specific with regard to music as the medium for the group and achievement of goals. I have led a lot of different groups in the past which have used different meaningful activities for a therapeutic process and achievement of goals but there appeared to be something extra special going on here. I think what music playing enables is an immediate link and engagement with all other members present e.g. You hit a drum and you get immediate feedback of your contribution to that moment in conjunction with everyone else. With a gardening group for example although highly therapeutic for all the aforementioned symptoms and providing other benefits perhaps not gained here your contribution may not have such an immediate connection with other group members. For this reason I feel the music fits very well with mindfulness principles of totally being in that moment and therefore has the potential for all the associated benefits to mental health and wellbeing over time. Then of course there is all the evidence linked to the power of music listening and rhythm and the positive effects on neuroplasticity. Therefore the drumming and the practicing rhythms seemed to be particularly engaging and useful for this. I can think of some people who appeared to manage more movement, more concentration, more

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tolerance relevant to their goals within the drumming and rhythm aspects of the project. I do feel that having the performance to aim for also gave some patients an end target and added to their enthusiasm. So the process of each group but also the performance as a product were important.

- Having the opportunity to practise in a group at the venue on a regular basis
- Rehearsals better for getting people standing and using their affected arm.
- Most were working on them in a way that they wouldn't of had the opportunity to do so had they not taken part in the project.
- Working towards a concert performance, highly skilled musicians helped create a very special piece of music beyond the patient's expectations. High ratio of therapy staff to patients helped really stretch people's engagement and work on goals. An environment was created where patients, musicians and therapy staff were equal. Transport was provided. I think we hadn't appreciated the scope and potential of the project so it felt that we were not as goal focused as usual. However, I think the success of this project has been that patients have come out the end of this project more ambitious for themselves.
- All projects, as the patients where all included throughout, on giving opinions, and naming the music they were creating, patients were able to work on physical goals, such as using their affected hand, and standing/walking with assistance. Many patients fed back to me that been in a group with other stroke survivors, helped them realise that others had the same problems, if not worse, and gave them more confidence to try anything.
- The interaction with other people who have survived a stroke

6. Which aspect(s) of the project did you find least useful for working towards patients' goals?

- Session length meant that some people could not participate - I'm not sure that this could be solved due to transportation time lengthening sessions
- It was all useful
- I found it all useful
- Not enough prep and time to talk to the patient before each session
- Performance time these had to be sacrificed a bit
- Not knowing what the goals were, but this was more our error and not the orchestra staff.
- We needed to be more active and structured between the RPO visiting. It took us some time to realise the potential for this project and feel confident ourselves. We'd had lots of preparation but it was actually doing it that made the difference.

7. What changes or additions would you like to see in future projects? Please consider the following aspects of the programme:

a. Session structure

- More aspects being patient led where possible. More drumming rhythm stuff - this to me was very energising and got everyone engaged.
- More patient led aspects if possible
- Breaks are needed; sometimes there wasn't time.

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- Keep the same but with agreed dates at the beginning of the project of our between sessions and who will run this - divided among all staff.
- Time to get settled in before starting the actual music practice at each session

b. Content

- More playing and more practice of the finished pieces
- More time for playing / drumming/following rhythms and creating the pieces- more time to practice the chosen pieces before the performance
- Perhaps a bit more structure, or specific things to work on between RPO visits to improve confidence of staff leading the group

c. Scheduling and/or frequency of sessions

- Every 2 weeks for sessions
- More notice of the sessions so they can be planned into diaries that are already full weeks in advance
- I would like to see nearly weekly sessions between HICSS and RPO
- The four days in a row of the last week was a bit much for some of the patients and it was very trying for some of them

d. Participants

- Involvement of more inpatient patients
- I would like more sessions on inpatient units and I feel as a service we plan to develop this.
- Any patient that wants to be there but to work on a goal that develops with attending the sessions.
- More joint sessions (AM and PM)
- We need information, testimonials etc. to try and help people feel like they can attend the group. I have a lot of people feel it's not for them

e. RPO team

- Good balance of team members
- All great
- This was all great
- The RPO team that already involved
- None
- No changes

f. HICSS team

- More involvement from all team members and disciplines
- Involvement of all of the team from early on. I do feel a timetable to enable staff to plan their time in for these sessions for the whole project would have reduced stress and increased the potential of engagement and confidence from all team members
- More opportunity for unit staff to get more involved. But only speaking on my behalf
- More notice!
- A more structured rota system for attending the sessions.

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g. Other

- Difficult to know how / what to change - the current recipe produced excellent results
- 3 days together is too much for most, i think it should of been alternate days.

8. Which aspect(s) of the project did you find most enjoyable?

- Seeing the patients develop and their confidence grow. Seeing their enjoyment
- Observing the increased energy, engagement, passion, laughter, positive energy from all involved - particularly those who were more cynical at the start. Realising the potential of this medium for future therapy but it also opened many doors in my mind about where else this can go.
- Being an equal part in a group, leaning music techniques and skills as an equal member of the group. It broke down the barriers of 'staff/patient'. Seeing patients laugh and enjoy and fully engage was fantastic and seeing people develop in confidence was brilliant.
- I very much enjoyed engaging with the patients and performing at city hall. Very humbling
- Making music
- When everyone played together on that stage at City Hall it was amazing.
- The end performance was incredibly powerful. Watching patient's grow in confidence and ambition.
- All of it

9. Which aspects of the project did you find least enjoyable?

- Difficulty trying to balance workload
- It was all useful
- Initial staff apprehension and trying to get everyone on board was stressful at the start and trying to do my other roles around the project. There was nothing not enjoyable about the actual project
- I found it least enjoyable when I could [not] attend
- Not enough loo access for patients. Wheelchair users often I think "holding on" during breaks
- It's been a lot of extra work in among trying to run the caseload as normal which was stressful. It was worth it though.
- Just the uncertainty of what to expect and to be expected of as in participation at the beginning

10. Which of the following, if any, do you think you gained from participating in the project? (NB: multiple answer choices were allowed)

- a. **Enjoyment:** 90%
- b. **Musical ability:** 60%
- c. **Interest in music:** 60%
- d. **Leadership skills:** 50%
- e. **Creativity:** 50%

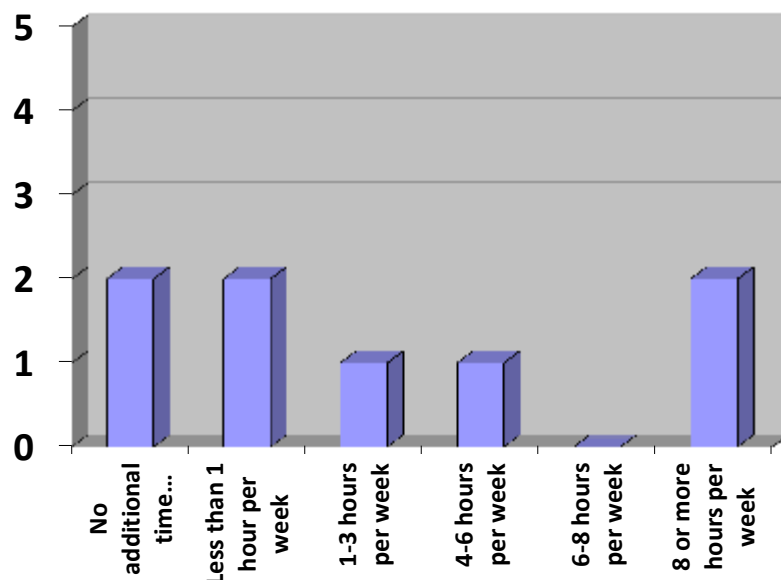
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- f. **Teamworking:** 70%
- g. **Inspiration:** 80%
- h. **Renewed relationships with patients:** 60%
- i. **Adjusted expectations of patient abilities:** 60%
- j. **New ways of working:** 60%
- k. **HICSS team morale:** 70%
- l. **Other (please specify):**

- Realising I do not need to be a musician to lead a creative music group. Having opportunity to lead a group gave me confidence of my own potential in taking this forwards with the team
- A realisation that I don't need to be a musician to run a creative music group
- Team working and morale for those of us that were involved.
- I played several instruments when I was younger and I also danced. I played only occasionally and I never danced. I have now taken up two of my instruments again seriously and I've started dancing again. I'm happier and healthier myself!!!!

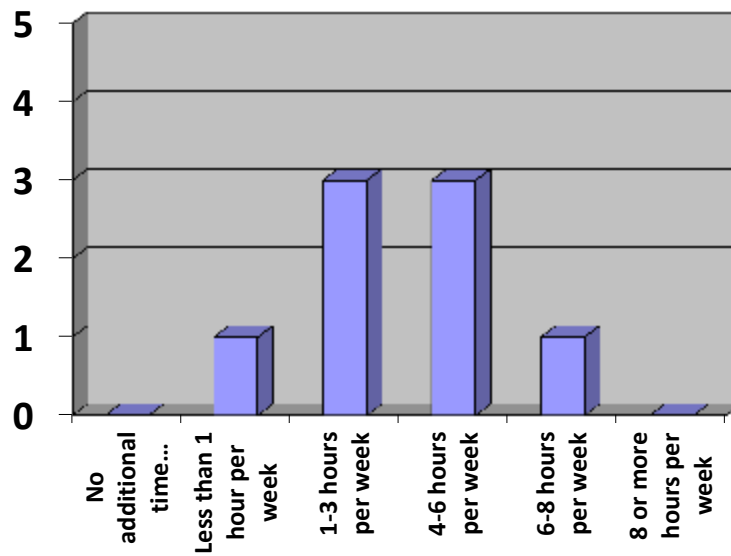
11. How much additional time did the project require in comparison to your normal weekly routine? Please consider any time spent preparing for sessions, time spent preparing patients for participation in the project, additional hours rearranging missed patients, etc.

a. During project planning/recruitment stage

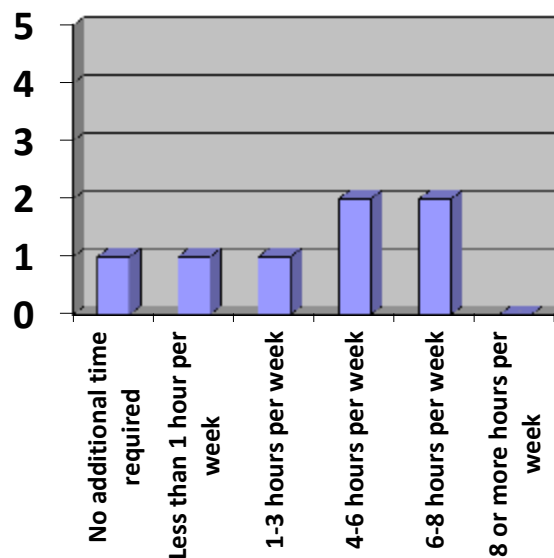


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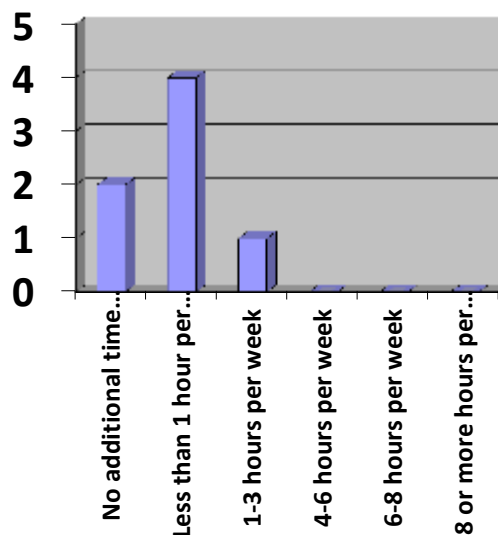
b. During weeks with RPO-led patient sessions



c. During weeks with HICSS-led patient sessions



d. During weeks with no patient sessions



Appendix 7.7 – Case Studies

Case Studies

Four case studies were prepared by a Clinical Psychologist and Occupational Therapist taking part in STROKESTRA sessions.

Case study 1

A 68 year old male who had a stroke in May 2014, had had a previous stroke in 1990, resulting in left sided weakness. The most recent stroke resulted in increased left sided weakness and dysarthria. He had previously been self-employed working in the construction industry. Due to being unable to return to this following the first stroke, he set up a voluntary organisation supporting people around welfare rights. He did not feel able to continue this following the second stroke due to increased disability and speech problems, as he frequently represented people in court and liaised with others on the telephone in this role. He also felt he was unable to return to his other hobbies following the second stroke, mainly cooking and calligraphy (also impacted on by other health conditions).

Due to his stroke related difficulties, he became increasingly dependent on family members. The lack of independence and activity resulted in him spending all of his time at home. This resulted in low mood, anxiety at going out poor quality of life. He was referred to the music rehabilitation project by Clinical Psychology with the goals of increasing his confidence, re-establishing social activities and improving mood. He had an interest in classical music and opera, so was keen to attend, although attending the sessions was difficult due to having to get a wheelchair taxi alone, and due to his anxiety at leaving his home which he described as the 'safe zone'.

Despite his anxiety at attending the group, he attended the sessions consistently. He was initially apprehensive in the first sessions, however as the project went on he began engaging more in the activities and conversing with others.

In his feedback he explained how attending the sessions helped him go out and participate in an activity. He said 'It forced me to go out and enjoy what was waiting at the other end. Because it was small doses a couple of hours and then back to safe zone, I could do it. I got home and thought "I could do that again"'. He described attending the sessions as a 'calming two hours where thoughts of ending it didn't enter my head'

He also discussed the other benefits attending the group had, for example he explained 'mobility wise, I had to force myself to stand and walk and sit in my wheelchair. It forced me to get a shower! I often don't because I have to rely on someone to help me and they are not always around. It was something to look forward to.'

Also, of the project he said it 'stopped my brain lying dormant and forced me to think about different areas. After first stroke in 1990 I got myself back into maths to use my brain (e.g. trigonometry), I suppose music has replaced the maths'. Being involved in the performance at Hull City Hall also benefited him, with the patient reporting, 'I had the same satisfaction I got when I built a road, when you can stand back, look and say "I've done that".'

He also kept a diary during the project. To complete this he also started to do calligraphy again, something he had not felt able to or confident to do prior to this.

Appendix 7.7 – Case Studies

Case Study 2

A patient with mild receptive and expressive dysphasia experiencing difficulty following complex commands and difficulty in sentence formation scored a 70% on the COAST scale (Communication Outcomes after Stroke) prior to taking part in the STROKESTRA project. The patient also experienced low mood and on-going fear regarding seizures which resulted in anxiety as he watched the calendar waiting for his next seizure. Wheelchair bound, he lost confidence in standing and mobility linked to residual weakness in his left lower limb and fear of having a seizure while standing or walking.

The patient was referred to the project by his Occupational Therapist with the stated goals of increasing in self-rating of communication and confidence (measured by increased score on the COAST outcome measure and self-reported questionnaires), improved mood and reduced pre-occupation with seizures (measured by Stroke Impact Scale and self-reported questionnaires), and increased confidence while doing tasks in standing and when mobilising (measured by scores on SIS and self-reported questionnaires). The patient attended the music sessions regularly, often accompanied by his nephew who helps care for him, and reported enjoying the project immensely.

The patient often contributed to group discussions despite speech difficulties. Following the project, the patients COAST score improved to 78%, with a ranking of 10 out of 10 in confidence when communicating. His answers to Stroke Impact Scale questions regarding his ability to communicate and understand what was heard or read improved from 'very difficult' (understanding what is said in conversation), 'somewhat difficult' (having a conversation on the telephone) or 'a little difficult' (participating in conversations) to 'not at all difficult' on all but one category. Through the evaluation survey, the patient explained, 'music helped me relax and not worry about communication.'

All Stroke Impact Scale measures of mood improved (see graphic below), and qualitative responses to evaluation surveys supported these changes with responses such as, 'The music project kept my mind occupied' and 'helped me relax in my mind more and with epilepsy symptoms. It stopped me thinking about stroke and helped me sleep better. People told me I appear more happy.'

Patient Mood Responses

Feel sad

Pre – some of the time
Post – none of the time

Feel there is nobody you are close to

Pre – a little of the time
Post – none of the time

Feel that you are a burden to others

Pre – some of the time
Post – none of the time

Blame yourself for mistakes you made

Pre – all of the time
Post – none of the time

Feel that life is worth living

Pre – none of the time
Post – all of the time

Patient Standing & Mobility Responses

Strength of affected leg

Pre – a little strength
Post – some strength

Strength of foot/ankle

Pre – no strength at all
Post – some strength

Moving from bed to chair

Pre – somewhat difficult
Post – not at all difficult

Walking one block

Pre – could not do at all
Post – somewhat difficult

Walking fast

Pre – could not do at all
Post – very difficult

Appendix 7.7 – Case Studies

Case Study 3

A patient experiencing low mood and depression, reduced fine motor skills and upper limb activity, and slow thought processes and communication was referred to the STROKESTRA project in May 2015. Before taking part, the patient scored a 24/27 on the Patient Health Questionnaire (PHQ-9) and a 9/21 on the General Anxiety Disorder scale (GAD-7) indicating severe low mood and anxiety.

The patient used the project to work towards goals including increased confidence with communication, increased speed of thought, improved fine motor skill and involvement of arm in function, and improved mood as a result of the development of a new leisure activity and social network. He attended sessions regularly alongside his wife, who cares full time for him, and particularly enjoyed playing the electric guitar during workshops and the final performance.

Following the project, the patient improved to 9/27 on the PHQ-9 and 3/21 on the GAD-7, indicating improved mood and lessened anxiety. Stroke Impact Scale questions regarding mood improved on 6 items, including improving from 'feeling as though I have nothing to look forward to' from 'all of the time' to 'some of the time'. Qualitative feedback on self-report questionnaires supported this improvement, with the patient saying he 'thoroughly enjoyed' the project, and felt it 'lifted mood and morale' and gave him 'something to look forward to'. The project also enabled him to develop a new interest, and rekindled his desire to play the electric guitar again as he had done at age 18.

Cognitively, Stroke Impact Scale questions regarding the ability to think quickly, concentrate and remember to do things improved, with the patient reporting the project 'helped me concentrate'.

3 out of 7 communication items on the Stroke Impact Scale improved, with his ability to 'understand what has been said in conversation' improving from 'somewhat difficult' to 'not at all difficult' following participation. The patient also reported the project benefitted his 'social interaction in every way'.

A baseline Chedoke Upper Limb Assessment showed the patient was able to complete most tasks but with a great degree of difficulty and low speed. Following the project, the patient was again able to complete all tasks, but with a lesser degree of perceived difficulty and increased speed. An Occupational Therapist also noted significant improvements in patient movement:

In earlier sessions, the subject was unable to select and press strings without excessive shoulder hitching to compensate for lack of selective movement and dexterity. He reported a degree of discomfort and frustration when trying to select strings. Over time, with advice regarding technique and positioning/posture and some hand over hand guidance, he gradually improved and by the end could independently select strings and play with greater ease and satisfaction. We also adapted the type of guitar to enable greater ease due to the narrower 'stem' of the electric versus acoustic guitar and less pressure required on strings.

The patient also improved on Stroke impact Scale questions regarding strength and use of the arm most affected by stroke, and the patient reported that the project 'helped me work on finger/hand dexterity in a way I enjoyed, encouraged me to continue' and that he 'wouldn't be using my hand like I am now' without participating in the project.

Significantly, the patient's wife also reported improved mood, cognitive and physical skills.

Appendix 7.7 – Case Studies

Case Study 4

A patient presenting with emotional and cognitive difficulties post-stroke was referred to the project by his Occupational Therapist.

An occupational self-assessment undertaken before the project indicated a problem with the patient engaging in social activities that he enjoyed as much as he would like. PHQ-9 (16/27) and GAD-7 (8/21) scores also indicated low mood and feelings of anxiety. Stroke Impact Scale responses reported feeling sad some of the time and that he has nothing to look forward to 'all of the time'.

Cognitively, Stroke Impact Scale results indicated finding concentration and the ability to think quickly were 'somewhat difficult' for the patient and remembering things that had happened the day before was 'a little difficult' before the project.

The patient and his referring therapist therefore chose goals involving improvement in mood and reduction in anxiety through increasing engagement in a meaningful, enjoyable social activity, and improving self-rating of concentration and speed of thought, as measured by scores on the stroke impact scale.

A post-project occupational self-assessment indicated the patient improved in reported satisfaction for doing activities he likes. Stroke Impact Scale questions regarding feeling sad and as though he had nothing to look forward to also improved from 'all or some of the time' to 'none of the time'. Similarly, PHQ-9 and GAD-7 scores improved dramatically for the patient following participation in the project, with the patient returning scores of 0 out of 27 and 21, respectively.

Cognitively, the patient improved on memory, concentration and speed of thought items on the Stroke Impact Scale with the patient reporting no difficulty in 'remembering things that happened the day before' or 'concentration' following participation in the project.

Get in touch

Further information about the STROKESTRA programme can be obtained by contacting RPO Resound on resound@rpo.co.uk / Tel: 0207 608 8800 / www.rpo.co.uk/rpo-resound

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