



BIRMINGHAM CITY
University

**PROMOTING CHILDREN'S WELLBEING,
RIGHT TO MAKE CHOICES AND ENGAGE
IN PLAYFUL ACTIVITIES IN RESTRICTED
ENVIRONMENTS THROUGH MUSIC AND
SINGING**

**DR. CAROLYN BLACKBURN, FACULTY OF HEALTH,
EDUCATION AND LIFE SCIENCES, SCHOOL OF
EDUCATION AND SOCIAL WORK, BIRMINGHAM
CITY UNIVERSITY**

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Summary

This study represents a Froebelian exploration of the benefits for children attending Birmingham Children's Hospital in participating in Ex Cathedra's Singing Medicine project¹. The project offers play through singing games to children attending the Hospital.



The study takes a qualitative interpretive approach. Data collection methods included interviews with parents and professionals and researcher observations of Singing Medicine sessions. Further to this a focus group discussion was conducted with the vocal tutors from the Singing Medicine project.

The study is timely in light of the following comment in relation to the benefits of participating in music and singing in health settings, from the All-Party Parliamentary Group on Arts, Health and Wellbeing (APPGAHW) (2017a: 1):

Participatory arts in children's hospitals provide a pleasurable diversion from the anxiety of treatment and the boredom of long waiting times

Themes that arose from interviews included the important characteristics of the Singing Medicine vocal tutors; contribution to children's emotions; contribution to child/family experiences of hospital; contribution to children's development and learning (including neurodevelopment); spiritual and cultural dimensions; contribution to medical care (including contribution to the wellbeing of health professionals), contextual aspects of the project and contribution to family life, patterns and structures. The potential contribution to children's neurodevelopment is an

¹ Singing Medicine® is a registered trademark

important finding since it was mentioned by participants that neurodevelopment is an aspect of healthcare provision often omitted due to the understandable need to focus on acute care and patient survival and recovery.

From observations there was evidence of choices for children; following children's lead; facilitating medical care; building memorable moments for families and focussing on children's holistic development. From the focus group discussion with vocal tutors it was noted that there are important characteristics of and values held by the vocal tutors that relate to valuing children and families interests and strengths and empowering them, as well as ensuring that the project brings a positive dimension to their hospital experience.

These findings demonstrate the benefit of participating in the project for children, their family members and health professionals supporting them. The findings can be mapped against all six of the Froebelian principles promoted by the Froebel Trust. The project values childhood by promoting children's right to play and relax, whilst at the same time valuing children's interests, identities, capacities as well as medical fragility. The project adopts a family-centred model of operation that values the bonds and connections between children and significant others in their lives. Connecting children to the outside world of nature, culture, community and society through singing games is evident throughout the findings. The central role of play and creativity is transmitted from the playful approaches adopted by the vocal tutors. Protection from harm and promotion of wellbeing is facilitated by the training provided for and characteristics of the vocal tutors, as well as the contribution of the singing games to children's (and families) sense of happiness and wellbeing.

The findings can be considered in light of significant evidence from the APPGAHW on the benefits of the Arts more broadly and singing and music specifically in health settings, and also in light of the United Conventions on the Rights of the Child. In particular Article 31 which states that every child has the right to relax, play and take part in a wide range of cultural and artistic activities and Article 12 which states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life.

Introduction and background to the study

Birmingham Children's Hospital (BCH) is a leading UK specialist paediatric centre, offering expert care to 90,000 children and young people from across the country every year. The hospital provides care and treatment for the most complex heart conditions, chronic liver and kidney disease, cancer, serious burns, epilepsy, neurology and cystic fibrosis. It is also home to Europe's largest single site paediatric intensive care unit, a 24-hour accident and emergency service, regional major trauma centre and new mental health service for 0-25 year olds.

Children attend for a range of reasons and can stay for short, medium or long term depending on the type and severity of their condition. Although the hospital promotes a respectful and participatory ethical approach to care and treatment for children, one result of chronic and long-term illness is a reduction in children's ability to make everyday choices about their world, combined with stress and restricted play opportunities. Ensuring that children's well being and education is not disrupted is a priority alongside delivering their health and medical care. For this reason, there is both play and education provision on-site. Included in this is a fully-equipped school, a play centre and a Singing Medicine project.

The Singing Medicine project <http://excathedra.co.uk/education-participation/singing-medicine/> is an award-winning project² that is delivered weekly to all wards and in-patient areas at BCH by Ex Cathedra vocal tutors, including children who are very ill. Singing Medicine has been delivered at BCH every Friday since November 2004. The project brings all the benefits of play through singing to children staying in hospital using a repertoire of songs written by the vocal tutors themselves with additional well-known singing games. In an environment where children can feel they have lost control over their lives singing games offer children ways of making decisions. The games also support areas of children's learning and can be adapted to meet children's individual needs as required. The deep breathing required by singing enables participants to reconnect with core muscles, and helps increase lung capacity. Singing activities often include some movement to increase physical mobility, and vocal tutors are often approached by physiotherapists to work with a child in a particular way in order to increase the development of particular muscles in conjunction with exercises they have set. Working in child or family groups singing sessions relieve boredom, offer a distraction from the ward around them, and reduce social isolation. Singing with others promotes human bonding and oxytocin, supporting children's relationships with caregivers. This in turn can lead to an increase in wellbeing in a situation where psychological deterioration can lead to deterioration in health.

Objectives

This research study aimed to explore the views and perceptions of parents and professionals who care for and support children who participate in the Singing Medicine project as part of the wider Play Department offer to children and their families. A further aim was to understand how the application of Froebelian principles can help us to understand and conceptualise children's rights

² Outstanding contribution to the field of arts and health, Royal Society for Public Health 2011

and wellbeing in the context of their family and community in restricted environments such as a Children's Hospital. Froebelian principles are:

- The integrity of childhood in its own right.
- The relationship of every child to family, community and to nature, culture and society.
- The uniqueness of every child's capacity and potential.
- The holistic nature of the development of every child.
- The role of play and creativity as central integrating elements in development and learning.
- The right of children to protection from harm or abuse and to the promotion of their overall wellbeing.

Theoretical concepts

The study takes a bio-psycho-social approach which acknowledges that children grow and develop in a social and cultural context influenced by the bi-directional interactions and relationships within and between the environments they inhabit that interact with their own unique characteristics and personalities. These contexts include proximal contexts such as home (Microsystems) and more distal contexts such as policy influences (macrosystems). Mesosystems represent the linkages between Microsystems (such as home and hospital) and exosystems represent contexts which influence children indirectly such as parents' workplaces. Children's learning and development is therefore socially and culturally constructed through interactions and relationships with others in environments where meanings and languages are shared as summarised by Bronfenbrenner (2001: 6965):

Over the life course, human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving bio-psychological human organism and the persons, objects, and symbols in its immediate external environments. To be effective the interactions must occur on a fairly regular basis over extended periods of time.

The personal activity, setting, caregiver and child characteristics are most likely to be most potent in affecting the course of development. They include those characteristics that either encourage or discourage children's engagement with features of their environments such as people, symbols and artefacts that

'set in motion, sustain, and encourage processes of interaction between the [developing] person and two aspects of the proximal environment: first, the people present in the setting; and second, the physical and symbolic features of the setting that invite, permit, or inhibit engagement in sustained, progressively more complex interaction with an activity in the immediate environment' (Bronfenbrenner, 1993: 11).

Of particular relevance to this study is Bronfenbrenner's attention to an individual's interaction with the world of symbols and language (semiotic systems) within microsystems which he believed to be significant in understanding the formulation of people's intentions, goals and actions towards

each other (Lerner, 2005). This is because music (as mode of symbolic language) is noted to be used for relational and practical purposes by parents such as calming, soothing and motivating children, contributing to the routine and structure of children's daily habits, such as nap times and meal times and promoting parent-child interactions (Young, 2008; Lamont, 2008; Williams *et. al*, 2015). This project takes this model into account by acknowledging that children's experiences in the microsystem of home are influential in their experience of medical and health care and vice versa.

Children's families and professional reports of children's experiences of the Singing Medicine project therefore needed to be considered.

Research questions included:

1. What are the views and perceptions of parents on the role of music and singing in children's wellbeing, right to make choices and decisions and engage in playful activities during their Hospital stay?
2. What are the views and perceptions of professionals who work in the Hospital on the role of music and singing in children's wellbeing, right to make choices and decisions and engage in playful activities during their Hospital stay?
3. How can the application of Froebelian principles help us to understand the children's rights and wellbeing in the context of their family and community in restricted environments such as a Children's Hospital?

Methods

The research approach involved a qualitative interpretive design. Interviews were undertaken with parents of children who are currently visiting their child during their stay at the Hospital and professionals who are providing support and care for the child/family. Non-participant researcher observations of musical play sessions were also undertaken on three occasions where it was not considered to intrude on children's privacy or interfere with their enjoyment of the sessions. The aim was to select a maximal variation sample of children / families aged birth to eight from diverse social and cultural heritages and with a diverse range of healthcare experiences to participate. Similarly, as broad a range of professionals were invited to participate. In practice, opportunity sampling was adopted as it proved difficult to identify parents who agreed to participate and had sufficient time to participate in an interview on visiting their child in Hospital.

Interviews followed a semi-structured interview schedule that provided the opportunity for participants own reflections on their experiences and knowledge. Interviews were digitally recorded, anonymised by use of a code and transferred to a computer hard drive. Data was analysed at the *a priori* level to answer the research questions first, following which themes were identified with both common and discrepant themes being reported in order to reduce bias. The themes have remained as close to the descriptions and concepts provided by participants as possible.

Ethical considerations

Ethical considerations related to participant informed consent, right to anonymity, right to withdraw at all stages of the research and to power relationships between researchers and

participants. Additional concerns relate to participants who may be emotionally and psychologically vulnerable due to their child's long-term health care needs (parents) and/or emotional and physical stress due to providing long-term care (parents and professionals). The researcher is an experienced researcher who has worked on numerous projects involving children, families and professionals as participants and takes a reflective, responsive stance to the verbal and non-verbal signs and signals that participants utilise to demonstrate their emotional state. The researcher familiarised herself with Hospital safeguarding procedures and a Research Passport was obtained from the Hospital before data collection commenced which offered an additional layer of ethical and safeguarding protection. Ethical approval was given by the Faculty of Health, Education and Life Sciences Academic Ethics Committee and North of Scotland Research Ethics Service (REC reference: 16/NS/0117 IRAS project ID: 210539).

Review of literature

Benefits of participating in musical activities

Singing is noted as a universal human activity (Powell and Gouch, 215) and a conduit for emotional exchange (Elkind 2015; Spratt 2012). There have been claims from researchers in a number of disciplines such as psychology, music and health about the benefits for children from engaging in a wide range of musical activities. Hallam (2015) notes the benefits for children's intellectual, social and personal development. She illuminates specifically the advantages of active music making for children's aural perceptive and language skills, literacy skills, aural and visual memory, spatial reasoning and mathematics, intellectual development, executive functioning and self-regulation, creativity and general attainment. Further to this, she proposes that musical activities are recognised as contributing to children's personality, the engagement in education of disaffected children, social cohesion and inclusion, pro-social behaviour, empathy and emotional intelligence, psychological wellbeing, personal development and self-esteem, health and physical development. It is important to note that she is talking about active involvement in musical activities that involve an instrument and notes some important characteristics of music learning sessions that underpin these claims as well as the methodological issues in studies upon which these claims are made. A literature review published in the USA explored ways in which early childhood engagement in not only music-based activities (including singing, playing musical instruments and dancing) but also drama and the visual arts and crafts was linked to socio-emotional development. The review compiled research showing a positive association between the development of socio-emotional skills and all the branches of the arts under investigation (Hallam, 2015).

Overall, Hallam (2015) suggests that there is sufficient evidence that engagement with music plays a major role in developing perceptual processing systems which facilitate the encoding and identification of speech sounds and patterns, the earlier the exposure to active music participation and the greater the length of participation the greater the impact. Transfer of these skills is automatic and contributes not only to language development but also to later literacy (Hallam, 2015). Lonnie (2010) points to the growing imperative to value young children's entitlement to musicality and cultural expression which may require a reframing of a dominant approach that values transfer effects of music making. Furthermore, there is call for caution in the interpretation of claims that music can influence children's achievement in other areas as there is concern that such claims of transferable benefits are 'being exaggerated and based on over-simple cause-and effect readings of research evidence' (Young, 2007: 291). Nevertheless, the benefits for children's

overall wellbeing and expression of choice, not to mention benefits for learning and development and additional health benefits are highlighted in Hallam's work.

Arts in health settings

Health is described as a 'state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (World Health Organisation, 1946). This definition takes account of the principles of public health, psychosomatic medicine and behavioural medicine and other related fields such as health psychology. The World Health Organisation defines the social determinants of health as the 'conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life.' This includes social settings such as home, early years settings and hospitals. It can be argued that unequal distribution of power, income goods and services and participation in arts activities including music, singing and play creates differentials in health and wellbeing. Indeed, the All Party Parliamentary Group on Arts, Health and Wellbeing (APPGAHW) (2017) argue that arts engagement helps to mitigate the effect of adverse environments by influencing a range of human outcomes including child development. These principles have been integrated in the bio-psycho-social model which acknowledges the role of environmental factors in health and wellbeing and emphasises mental, social and spiritual dimensions of health (Engell, 1977; Bronfenbrenner, 1979).

Wellbeing is a term that can be difficult to define. In 2008, the New Economics Foundation (NEF) was commissioned by the Government's Foresight project on Mental Capital and Wellbeing to develop a set of evidence-based actions to improve personal wellbeing. They found that the concept of wellbeing comprises two main elements: feeling good and functioning well. Feelings of happiness, contentment, enjoyment, curiosity and engagement are characteristic of someone who has a positive experience of their life. Equally important for wellbeing is our functioning in the world. Experiencing positive relationships, having some control over one's life and having a sense of purpose are all important attributes of wellbeing <http://neweconomics.org/2008/10/five-ways-to-wellbeing-the-evidence/>. These dimensions seem consistent with the Froebelian principles highlighted by the Froebel Trust and are also consistent with the aims and objectives of this study and the Singing Medicine project. They might also be difficult to achieve for children (and their families) with long-term chronic health condition that require prolonged hospital stay and intrusive, painful medical treatment.

In relation to the health benefits of participation in the arts generally, APPGAHW (2017) and Fancourt (2017) highlight a wide range of possible ways in which the arts can support health and wellbeing of individuals, communities and societies in the context of contemporary models of health discussed above. This includes helping with specific identified conditions as well as promoting wellbeing, healthy behaviours and social engagement. Included in the broad definition of arts are singing and musical activities as well as performing arts such as dance, drama, juggling and visual art such as painting and drawing. Associated with the concept of social prescribing (which seeks to address health and wellbeing from a holistic perspective using a range of non-clinical interventions), participatory arts projects are growing in number in the UK (APPGAHW 2017b).

More and more people now appreciate that arts and culture can play a valuable part in helping tackle some of the most challenging social and health conditions. Active participation in the visual and performing arts, music and dance can help people facing a lonely old age, depression or mental illness; it can help maintain levels of

independence and curiosity and, let's not forget, it can bring great joy and so improve the quality of life for those engaged. Lord Bichard of Nailsworth, 2016 cited in APPGAHW, 2017b: 47)

Specifically, Fancourt (2017) points to benefits of participatory arts projects for:

- The brain (improve functioning of sensory cortex, auditory cortex, visual cortex, rhythmic processing centres, memory and emotion processing area such as the amygdala, medial orbitofrontal cortex and hippocampus);
- Physical function (helps with hand function and bi-manual ability and increased bone mineral density as well as reduction in fall risk for older adults);
- Biological markers (positively affect levels of neuropeptides, serotonin and dopamine and blood glucose levels as well as stress hormones);
- Cognition and development (temporal and spatial abilities, language and memory, learning and social development as well as supporting neurological conditions such as dementia);
- Stress, anxiety and pain (reducing stress or buffering its effects, reducing anxiety and fear and reducing short-term and chronic pain for different patient groups);
- Emotions and mental health (improvement in emotional state, enablement of emotional expression, mastery over and acceptance of emotions, improvement in mental health and wellbeing, cultural engagement);
- Health behaviours (ability and willingness to change behaviour and lead a healthy lifestyle);
- Sense of self (improved self identity and self esteem);
- Illness cognition (understanding illness and coping behaviours, adaptation to the illness and overcoming trauma related to illness);
- Social support (improves social bonding and reduces loneliness influencing mental health, wellbeing cardiovascular, neuroendocrine and immune function and mortality);
- Social identity and relationships (improved sense of collective self in the context of society with subsequent improvement in group cohesiveness including solidarity, team spirit, upholding and reinforcing cultural traditions and improving morale);
- Social behaviours (promoting pro-social behaviour, reducing conflict and enhancing collective action).

Singing and music in health settings

In relation to the benefits of participating in music and singing in health settings, the APPGAHW (2017a: 1) revealed that:

Participatory arts in children's hospitals provide a pleasurable diversion from the anxiety of treatment and the boredom of long waiting times

Furthermore, Fancourt (2017) and the APPGAHW (2017b) point to the following benefits for participants and recipients of singing and music in healthcare settings:

- The brain – grey matter in the brain contains the cell bodies of neurons. Listening to music induces structural changes in the grey matter in people who have had a stroke;
- Other organs - singing has been shown to enhance lung function including forced vital capacity, forced expiratory volume and breathing control. Listening to and making music have shown to affect blood pressure and heart rate variability. Fancourt (2017) suggests this implies that music alters the activation of the sympathetic and parasympathetic nervous systems (two branches of the nervous system that involve bodily function including breathing, heartbeat and digestive processes). Music has been shown to impact on the digestive system including increasing gastric myoelectrical activity, gastric motility and gastric emptying and reducing nausea and vomiting;
- Physical function - rhythmic music has been shown to support improvements in gait velocity, stride length, cadence and standing ability in people undergoing physiotherapy. These changes have been seen in healthy individuals as well as those affected by strokes, spinal cord injuries and brain trauma;
- Cognition and development – music therapy has been found to support development, behavioural adjustment and emotional regulation in children with autism;
- Stress, anxiety and pain – there is some evidence that music may evoke activation of the descending analgesia pathway in the brain and lead to a reduced need for sedatives and analgesic;
- Social behaviours – music has been shown to be a proxy language for new babies and people with developmental delays and learning difficulties such as autism.

Added to this, there is an imperative for the inclusion of singing and music in the augmentative healthcare provision for dying patients for the benefit of healthcare professionals:

In the care of the dying, healthcare professionals needed five forms of literacy: medical, physical, emotional, moral and cultural. As cultural literacy is undervalued in medical education, young doctors are deprived of a potent resource for making sense of both life and death. (APPGAHW, 2017b: 150)

In terms of children’s rights to engage in creative activities and make choices, the United Conventions on the Rights of the Child stipulate in Article 31 that every child has the right to relax, play and take part in a wide range of cultural and artistic activities and Article 12 states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times, for example during immigration proceedings, housing decisions or the child’s day-to-day home life.

Given the evidence reported above, this study is timely and focuses on one aspect of music and singing in healthcare settings; the benefits of singing games for children with a range of conditions at a children’s hospital in terms of their right to makes choices, engage in playful activities and their overall wellbeing (research questions are stated in a previous section). Findings from interviews and observations are discussed below.

Findings

Twenty participants were involved in semi-structured interviews as shown below:

Parents	Professionals	Siblings	Children/young people
<p>Five parents (four had children attending BCH currently. One parent had a child who attended previously and had since passed away).</p>	<p>Three play workers, two chaplains, two consultants, one pediatrician, one research nurse co-ordinator, one family liaison nurse, one clinical lead nurse (PICU), one haemodialysis unit sister, one physiotherapist, one teaching assistant</p>	<p>One sibling</p>	<p>One adult who had attended BCH as a child</p>

Table 1: details of interview participants

Participants’ details are shown in Appendix A. The intention was to recruit 10 professionals and 10 parents. The process of recruitment involved the Singing Medicine vocal tutors approaching health professionals to inform them of the study and identify possible professional participants. The criteria for inclusion were participant knowledge about the Singing Medicine project and willingness to participate. As diverse a sample of professionals as possible was intended in terms of professional role and demographic characteristics. For those professionals who were willing to participate, the researcher emailed them and included a participant information leaflet and consent form allowing seven days for professionals to make a decision. Parents were identified by the vocal tutors in collaboration and consultation with professionals and a similar process followed, however parents were given 14 days to decide whether to participate. Approximately 10 parents initially confirmed to vocal tutors and health professionals that they were willing to participate but four of

these did not reply to emails from the researcher which left five parent participants. One parent proposed that her daughter participate as a sibling. For the adult participant who had participated in Singing Medicine as a child, she was approached by the vocal tutors initially and then by the researcher once confirmation of an interest in participation had been received by the vocal tutors. To compensate for the shortfall of parent participants, additional health professionals were recruited.

Findings from the project are presented and discussed in the sections below starting with findings from interviews, followed by observations and finally findings from the focus group discussion with the Singing Medicine vocal tutors.

Interviews

Findings from interviews will be reported under the broad headings of:

- Descriptions of the Singing Medicine professionals
- Emotions
- Children's/families' experiences
- Contribution to development and learning
- Contribution to spiritual and cultural dimensions
- Contribution to medical care
- Contextual comments
- Contribution to family life, patterns and structures.

Singing Medicine professionals

A strong theme that emerged from analysis of data was the role of the personalities and characteristics of the vocal tutors involved in the project. The Singing Medicine vocal tutors were specifically referred to in very descriptive ways, for example:

- They are fun and enjoyable
- They are gentle
- They are inclusive
- [They are] ...People with smiley faces
- They bring a predictable pattern to the ward
- They have a very positive effect on the children
- They provide entertainment
- They provide distraction

- They are educational
- [They are] ...People in purple shirts:

*So two people in purple shirts, they appeared with smiley faces, they introduced themselves and they invited us from our bay to the playroom for a Singing Medicine session. I wondered what it was about. And from the first moment we entered the room there were chairs in a circle, a number of children were sitting on them and **these people in purple** started singing and involving children in the singing and playing instruments. It was wonderful and a lovely session. C enjoyed it so, so much that he kept asking every single day, Mummy, when will the Singing Medicine people come again? And then at some point we knew that there is a pattern and they come every Friday at 11 o'clock and there is a half an hour session so it became part of our hospital life, a very important one. Even post-transplant, the week after C's transplant, the Singing Medicine people, they knocked our cubicle door and they asked if we were happy to invite them inside. Although he wasn't well, C was more than happy to see them and take part in a session. And every time whenever it took place, and we were participating, C got crazy with singing and with playing a variety of instruments, so I could easily say that it had a very great and positive impact on him, really cheering him up. He really looked forward to Fridays and luckily now we are post-transplant and we just came for the clinic twice a week, it happens on Friday too, so we see Singing Medicine people, they still come and C still equally enjoys sessions with them. (Participant 3)*

Emotions

A number of comments were made by parents and professionals in relation to the effect of the Singing Medicine project on children's emotions:

But also healing emotionally and healing in a broader sense I think. It's providing a positive experience but it's more than just normalising play I think because we can do normalising play. It's more tailored to the individual child and it is something that's almost a prescriptive thing, so we do referrals as specialist play service. (Participant 4)

Four participants mentioned the emotion/mood changing capacity of the project saying that it calms children or it 'cheers children up', and distracts them from unpleasant medical procedures. It can also act as a stimulant for children who are depressed:

So I think that music can be highly soothing, and I've often watched the benefits for children who are highly stressed. Just by having some music can change their whole environment, and be calming. It can also work as a stimulant. So for a child that's perhaps depressed and not wanting to engage in anything that you're doing, just by changing the noise, just by implementing some music can actually just be a real stimulant and a positive experience for them. (Participant 13)

The comment above suggests that the singing games can help to positively alter the acoustic ecology of hospital spaces. A couple of people mentioned that the project helps to build memories for parents and families to draw on 'if the worst happens' when children do not recover from their illness. Other comments in this theme were that the project is 'empowering' and something

children can choose, 'it enables children to make choices' or 'you can see the happiness on children's faces when they're singing.'

Children's/families' experiences

There were a number of comments made in relation to the way that the Singing Medicine project influenced the experience that children and families had at Birmingham Children's Hospital in a positive way. For example

Some of the children have unpleasant, intrusive and painful medical interventions for example haemodialysis – the Singing Medicine project is something they choose rather than something they have to do or have to have done to them. (Participant 6)

Three participants commented that the project brings a sense of normality for children whilst three others said that the project brought a wider variety of faces for the children to see and another six said that the project was 'something nice' for the children to look forward to in the midst of unpleasant experience of medical interventions. One parent said that the vocal tutors provide an individual experience for all children. Four participants commented that the project was something they can choose rather than something that is done to them, whilst another participant described the project as 'a glimmer of light'. Another participant discussed the way in which the project helps children to connect previous musical experiences with their hospital experience as it provides 'familiarity with previous music experiences in a familiar environment.' Most profoundly a couple of participants commented on the possibility for the project to help children and families build positive experiences of their hospital stay and to help them to forget why they are visiting the hospital:

Enables children to take a positive memory away from hospital, rather than remembering only that they had blood samples taken, they might also remember the pleasant experience from the Singing Medicine people. (Participant 1)

Because it's also, you know, when the child is happy the family is a bit more relaxed and, you know, it's not only the child but it's also the family and the family members that benefit from it. (Participant 17)

One participant liked the structure that the project brings to children's week.

Development and learning

The Singing Medicine project was thought by participants to contribute to children's development and learning in the following ways. Firstly it was noted to provide opportunities for educators to observe children and align what they observed with the Early Years Foundation Stage (EYFS) goals or other curricula. Connected to this the vocal tutors were reported to work with education targets determined by educators within the project to facilitate children's learning and development:

This one child is like, they start something and she'll go 'next one'. So we are trying to get her to sit for a whole... because she loves it but we are trying to encourage her to sit for a whole song, so they are kind of helping with her education as well really. And like with our babies it is teaching them maybe to hold a rattle and, you know, at the start you might be having to keep putting in that hand and by the end they are

holding it, so you are helping them reach their potential and encouraging them to see what they can do. (Participant 1)

Three participants thought that the project facilitated opportunities for socialisation:

Some of them [children] come in and they are quite shy when they come in, so they don't tend to mix with the others straight away. So it can be a good ice breaker as well. [It] gets them to interact with other people round the ward. And everybody as well, so the little toddlers come and join us as well, it's not just the school children. Everyone on the ward is invited to join in, and we join in as well as teachers. Not every week but some weeks we will sit and join in with them to encourage them to take part as well. (Participant 18)

Children love videos and TV and computers but that's not enough on its own. They also need people and when you can't move, if you're not mobile then it makes a difference if people come to you. On the ward my daughter was on they have a lot of people who come to them like the Singing Medicine project. That really makes a difference. (Participant 7)

A couple of participants also mentioned that children were learning new songs, learning to beat a rhythm, learning actions to songs and increasing their vocabulary:

They are learning some new songs, some new skills, they are learning to beat a pulse on the drum, and all these sorts of things and actions to songs. They're encouraged to change some of the words in songs, so there's a huge amount of interaction in it, and I think that's really good for them. (Participant 18)

It was also thought to help children with learning colours, numbers, new objects, to encourage creativity and expression, to promote motor development, hand-eye co-ordination and neuro-development which 'health professionals don't always have time to think about.'

I suppose from a neurodevelopment point of view, if I think of particularly the neonatal population, it's not something that we're very good at, to be honest with you, in intensive care. Because I think we're so focused on the acute stuff. So you've got this baby who's maybe two or three months old, they're lying in this thing like that, and if they are a little bit awake, and they're a little bit unsettled, and the Singing Medicine comes in, it's almost they become quite aware, actually, which is really, really nice. (Participant 5)

Linked to this a couple of participants mentioned the way in which the vocal tutors work with children's individual interests and adapt to children's preferences. They do this by 'getting to know' each child:

Like if you've got a long term patient and we did have one long term, they had been here for months and they had got to know their names. Even if there are different people coming on every week she got to know their names and she got to know the songs and they adapt according to the child. So say we've had one in the past where I've come up and I said he loves frogs, you can't get smiles out of him unless it's to do

with frogs and then they'll sing a frog song or they'll have a frog or, you know, it's just magic that they can adapt it to anybody. (Participant 1)

They can go from a child who might be seven or eight that has no verbal communication, a little bit of physical communication maybe with hand gestures and things, then smiles and gives really good feedback, then they can go from that to a tiny baby who will give you very little feedback at all and their ability to adjust to every child is really lovely. I think they really understand that we have such a variety of patients here, and a variety of people, from different backgrounds, they look at that child and they come up with so many different things that they can do. The ones who are a little bit more able, they have a bear dancing on the bed that they do, and the child can choose what they do next. So the bear dances on the bed and they can say, where shall we dance next, and the child will say where they dance next. I think that they look at the uniqueness of every child really nicely. (Participant 9)

Spiritual and cultural dimensions

The way in which the Singing Medicine project promotes spiritual and cultural aspects of hospital experiences was mentioned by two participants. They discussed the benefits of the project in terms of the way in which it connects people from diverse backgrounds and enables children to experience a sense of achievement and participative empowerment as exemplified by the following comments:

[It] enables us to listen to children's souls regardless of religion, ethnicity, age culture or other characteristics, values and beliefs. (Participant 10)

In terms of the kind of spiritual direction that I'm involved with, that's where our energy is, that's actually where our potential, our life is, and so any time you can give that person a chance to connect with their energy is really positive. A child's been lying in their bed, feeling zapped of energy, feeling terribly sort of low or upset and cut off maybe, they come into a circle and they find that energy again, even a little bit. (Participant 8)

Even when one cannot sing well, there is something about an achievement. I think there is something about being able to sing a song that links into peoples' memories and their culture. One of the things that people would say is, it's about connection and where we find connection. And, that may or may not be within a religious framework but I think what singing does for people, it helps them connect, and connect with the people that they're with, connect with their past memories, connect with their communities that would sing similar songs, or maybe the same songs, connect with their past that they sung, you know? And, so, I think there's that around achievement and a sense of unity and connection, and belonging to a wider community and connection to different, kind of, psychological parts that supports wellbeing. (Participant 10)



Medical

In terms of medical aspects / value of the project comments were made by participants in relation to children's neurodevelopment, heart rate, experiences, mood and benefits for staff as well. One participant mentioned that the project 'enables us to think about experiences as well as medical care and also think about neurodevelopment from emotional experiences.'

Six participants mentioned that the project had positive effects for staff for example that it was encouraging for staff to see children enjoying themselves, that it had a 'positive effect on nurses', in that 'it reminds nurses that they are looking after a person first and a patient second' and that it positively influences the acoustic ecology of restricted spaces which is beneficial for children's wellbeing:

So I think it's calming, it's normalising in that there is often on intensive care there's not many things we can do because we are so restricted with all the equipment around and the negative noises. (Participant 4)

Two participants suggested that the project regulates children's heart rate and also helps with ventilation:

From an Intensive Care point of view, I've seen where the patients are much more relaxed and obviously that's going to benefit them medically because when you've got a patient who's very tense or they don't do anything or, you know, then they're struggling with their ventilation and, you know, they get very agitated and that can be quite difficult to manage and obviously will affect everything, you know, their blood pressure, their breathing. Whereas actually when they are relaxed and they are happy, and I think if they have a pleasant experience, they are much more relaxed, and obviously that does have an impact on everything really, so yeah, I think it can have a big impact on their condition. (Participant 2)

Almost all children in intensive care have continuous heart rate and oxygen saturation monitoring. There are children who are on a ventilator who have a life support delivered who are having monitoring for those things, blood pressure and heart rates that you would see normalising numbers from a distressed set of numbers to a more calm set of numbers over the time of the Singing Medicine session. (Participant 12)

A lot of it was just, sort of, calming, they would come and they would play some gentle instruments, you know, tapping blocks or chimes of some kind and they would sing a cappella into the bed space and then do some movements and interactions with the children. So, then the children would have different levels of interaction with them in return. So, there would be children who you didn't visibly see them do very much in response to the music, but actually, in some of those situations you could visibly see their heart rates, for example, come down as they were calming. Or you could imagine that they were feeling calmer. And there were other children who were quite distressed through the procedures days before and then you would see that they would be visibly more calm after or during the visit. There were other children that were able to interact and show pleasure or displeasure if they wanted to. And there were some children that, as you would expect, were very happy and showed signs of smiling and real enjoyment of being sung to and engaged with doing engagement with songs that they clearly learnt as sometimes the Singing Medicine came back repeatedly to the same patient. The families that could give us feedback were always praising the Singing Medicine project. And they would leave a purple sticker on the children to say that they had had therapy and that was also a badge they were quite proud of really. So, it generally left a positive sense of warmth in the bed space and you could get a sense that the children benefited from it. Measuring it is more difficult, but, you know, things like heart rate would settle and their facial expressions would look more calmed. (Participant 12)

Three people mentioned that the project can positively impact a patient's condition by making patients more relaxed (it changes their mood), whilst another said that it changes the tone of the bed space environment:

For example, alarms and people getting upset and pumps beeping and things, so there's the benefit in that the environment is normalised or it's made better for the child. (Participant 4)

There were also reported benefits for children who experience sensory impairment:

And I think there is benefit in yes... when a child is asleep I've seen it work really well, as well with children who might not react to sight or can't see. Or they might not react to touch particularly well because they are sensory overloaded or they've been used to negative touch rather than positive touch, but actually they respond really well to music or to singing or to certain instruments. If children don't respond to touch they may still respond to music or certain instruments. (Participant 4)

One participant felt that the positive experiences provided by participating in the project helps with healing, whilst another mentioned that it improves a child's experience of intensive care where:

They may at times be semi-conscious to might and not communicate verbally for a while, however, even though they can't speak, they can still hear music and experience something immensely positive. (Participant 4)

Singing Medicine was also reported to 'take away pain' from illness or medical procedures.

Contextual

Some comments made by participants suggested that the Singing Medicine project was particularly relevant in some contexts more than others or conversely not particularly suitable in some contexts, for example:

- Especially important for post transplant patients
- Not appropriate when someone is in a bed nearby and having a hard time
- Works well with children who haven't responded to other stimuli
- Good for children with mental health problems
- Works better with young/developmentally young children
- More suitable for children would need rehabilitation than children who are less stable
- Can be used in end of life situations

For me the benefits are enabling children to have positive experiences when their families are going through the kind of worst possible time of their lives really. So we've used it really beautifully around the time their child, before the child passes away actually and that's worked really well. (Participant 4)

- Can be a distraction therapy for some children. For example if children are placed in isolation for protection from infection:

One of the distraction therapies is reading books, but another distraction therapy could be just singing with the singing team and having their bloods done. The most beneficial effect I saw was in one of the children where she was in isolation, so there was nothing, you know, she was... I felt sorry for the child that we had to place her in isolation, to protect her from other infections that she could have rather than her passing on the infections to others. And for her this was a highlight of her week to a certain extent, having people coming into her room, interacting with her, having her own time, doing what she likes doing most and the effects could be seen on the weekend because she would carry on singing to us on the ward round. (Participant 17)

It's quite intense whilst they're on dialysis because you are trying to do to them, or to their body and to their blood, for four hours three times a week, so 12 hours, what the kidney does 365 days a year, 24 hours a day. Dialysis is only ten per cent of

kidney function and it's quite an aggressive treatment, so we can make them feel unwell but then they can't tell us how unwell they feel, you know, so they have to do all these things three times a week. They know on Friday that these jolly, happy people will come and sing and get them involved, doing instruments, going under a blanket, and all those sorts of things, and it's really lovely. They really look forward to Singing Medicine coming. It really is nice, and it's nice when you're walking past as well with all of them joining in and singing, and the staff do join in as well. We haven't got as good voices as Singing Medicine, we're not 100 per cent, but...I think the benefit is that they forget about the fact that they're on dialysis, so that blanks it out. They might not enjoy coming and having their dressings done and all the painful things that we do to them, but they enjoy the activities that happen during their dialysis sessions. (Participant 6)³

Families

Comments related to families were varied and included those that mentioned the way in which the Singing Medicine project helped with family relationships and those that helped families to cope with difficult and challenging situations:

- Something that siblings can do together
- Good to see my brother having fun and not in pain for that moment
- [We can] sing the songs as a family
- Gives parents time for respite
- Building memories with family for the future
- [It is] a reminder of the past (before illness)
- Enables parents to learn new songs with their child
- [Parents] can communicate with their child about that moment in time
- Helps parents see their child enjoying something and being happy

So for me the benefit is for the child but also for the family as well, because they might not have seen their child have anything positive for weeks and then this comes along and it's just that little glimmer of light for them really. (Participant 4)

- Encourages family participation and gives parents something to do with their child

And sometimes they would teach the parents, or the parents would pick up on songs as well. So, you could see that Singing Medicine would deliver the in tune version, the parents might deliver a slightly different version, but the children would benefit from the repetitive nature of that and the Singing Medicine might come back again and you could see the enjoyment from it. (Participant 12)

³ A description of dialysis can be found in Appendix 2

- Helps to re-build family bonds:

Music has been helpful for us to get closer to him because at one point he pushed us away when he realised what he was going through and it really hit him. But with the music, they were here he didn't want to say no and we got to get involved with him. There was one point when he...I think it really hit him hard, the things that he used to do, because he's not able to do them anymore. But then this [the Singing Medicine project] gave us the chance for us to do something together again as a family and obviously the staff doing it as well. So I think it is an opportunity to get closer to him. But then after that I enjoyed it myself. (Participant 16)

Observations

Three observations of the project were undertaken, the first in one of the activity room for oncology ward 15 where children come together to participate in play, creative and education activities, the second in the oncology ward 15 and the third in renal ward 1.

Room	Number of adults	Number of children	Activities undertaken
Activity room, Ward 15	Three vocal tutors, three parents	Three	Singing and playing instruments to several verses of 'This is How I Bungalow', 'Going on a Picnic' and 'Wheels on a Bus'. The children took turns to choose how to Bungalow, what to take on the picnic and actions for each of the songs. Parents joined in with choices, singing and playing instruments.
Ward 15, Oncology (child in isolation room)	Two vocal tutors, one grandparent	One	Singing and playing instruments to 'Walking in the Jungle' with several verses. The child was given a choice for each verse as to which animal appeared next. This was followed briefly by another action song before the child shows signs of fatigue and the tutors ended the session accordingly.
Ward 1, Renal Ward	Two vocal tutors, two parents	Seven children were present in the ward, but only two were well enough /wanted to participate on that day	Singing and playing instruments to verses of 'Going on a Picnic' and 'Wheels on the Bus'. Children were given choices about which songs to sing, which instruments to play and which verses and actions were included.

Table 2: details of observations undertaken

Themes that arose from analysis of observation field notes included:

- Giving children choices
- Following children's lead
- Facilitating medical interventions and overall patient care
- Building memorable moments for families
- Focussing on the holistic development of each child.

Giving children choices – in all three observations, children were able to choose whether or not they wished to play an instrument, what kind of instrument they would like to play, which songs / rhymes to sing, which verses and what items to include in the verses, for example which food to take on a picnic. Most importantly they could choose whether or not to participate, their own level of participation and when to stop. Their manner of expression was not always overt or obvious, however, and the vocal tutors continuously monitored children's level of comfort, fatigue and wellbeing. This meant that they were able to end an activity when necessary to ensure children's wellbeing was the primary indicator for decision making during delivery of the sessions.

Following children's lead – vocal tutors were observed to watch children's actions and listen closely to their expression and to change songs when the child appeared to lose interest, to narrate a child's actions with song (for example when a child on the oncology ward was tickled by his grandparent, the tutors created a verse about it and embedded this within the song being sung). Linked to this, the vocal tutors appeared to be following children's schemas. For example one child on ward 1 demonstrated an interest in banging (on a drum) and the vocal tutors quickly introduced a song about banging. Following this the same child started to 'blow raspberries' into the air and the vocal tutors changed the song to incorporate this.

Facilitating medical interventions and overall patient care – the vocal tutors noticed when medical / health professionals needed to apply an intervention / provide care and they responded accordingly. For example on ward 1, nursing staff were attempting to change tubes on a child's chest and stomach area. The vocal tutors introduced verses into the song they were singing with the child that prompted her to raise her arms and hands above her head, giving the nursing staff clear access to the required body area. More importantly the child appeared to be totally engaged in the singing and music games so less attentive to the intervention being applied. This high level of engagement in the singing and music games was also observed for all other children who participated. Children appeared to be content during their participation. They appeared to be receptive to participation and often quite enthusiastic. One child in particular on ward 1 changed during the activity from appearing rather restless to a more focused and content state.

In addition to this, the vocal tutors worked within the hygiene and patient safety routines embedded within the hospital ensuring that they and all equipment used was rigorously cleaned before entering a ward, before entering any isolation rooms, before approaching any individual child, and again after engaging with any child.



Building memorable moments for families – there were opportunities for family members (including parents, grandparents and siblings) to participate with their child, to learn new songs and activities and to build positive memories of their child’s experience in hospital. The activities provided by the vocal tutors focus on fun and enjoyment in contrast to the necessary but sometimes painful or uncomfortable procedures administered by health professionals.

Focussing on the holistic development of each child – the vocal tutors were observed to respond to each child’s individual choices and interests wherever possible. Within each activity, there were opportunities for the development of mathematical skills, memory, physical development, speech, language and communication, socio-emotional skills, singing and musical skills.

Focus group with Singing Medicine vocal tutors

There were eleven vocal tutors involved in the focus group discussion. Themes that emerged from the focus group discussion with the Singing Medicine vocal tutors include the characteristics of the Singing Medicine project and the benefits of the singing games for children and families.

Characteristics of the Singing Medicine project:

The vocal tutors described Singing Medicine as a project rather than a therapy. The role and skills of the vocal tutors themselves were also discussed. The vocal tutors have dual roles of teacher/educator and vocal tutor (although one is a nurse and a vocal tutor). They work across the range of Ex Cathedra’s education, community and arts in health projects, as well as in other settings for other organisations. The vocal tutors have singing skills and musicianship, teaching skills,

creative approaches, strong communication with each other, emotional intelligence and training for working in the hospital environment including infection control procedures to work on the wards.

As far as the project itself is concerned, the vocal tutors engage children in singing play during their stay in hospital, which has a wellbeing effect. The vocal tutors described their aims for the project as being to bring wellbeing through singing play to children in the hospital. In addition they aim to:

Inspire, enable and equip children to sing with the vocal tutors and then with siblings, parents and other family members.

The tutors visit children's bedside in pairs and, with the child, they play singing games together with the child. There is a particular house style in terms of structure and style of the songs that children can learn and this brings familiarity. This house style includes flexibility and creativity with the ability to adapt the songs to different age groups, competencies, skills, situations, interests and contexts. The project is continuous (it runs all year, including Bank Holidays such as Christmas Day). Ex Cathedra's education team, from which the Singing Medicine team are drawn, write their own signing games repertoire. Therefore most of the singing games come from this repertoire with the addition of some well-known and traditional singing games.

The team has recorded a CD for children and families to use in between visits, at home or in the car. However, the project offers more than playing a CD.

The project was described as inclusive. It is offered to everyone and the team adapts activities appropriately for any child who chooses to participate. It involves whoever is present with the child including professionals and for some parents provides a way to play and communicate with their child or permission to do so in an environment where they often cannot be involved:

I think the nurses quite enjoy being included as well, and the physios, being included in the songs themselves, and actually they sometimes will carry on once we've gone. The nurse or the physio will continue using the song, even if it's one of our songs and not Old McDonald, for instance, because they're catchy and they seem to value what they can do, even if it's not us delivering them.

There's a kind of unwritten set of permissions with a small session where parents have a set idea of they think oh, someone's coming to do a session with my child, this is the way it should be, I need to sit back and let them do what they do. It's interesting how you have to negotiate that quite a lot and bring people in or give people permission to go off and do their own thing and not be involved

I think as well for a lot of parents, depending on the reason that their child is in hospital, they may have a child who is normally fit and healthy and active and may have had an accident or something, and they don't know how to play with their child because their child now can't move or can't do something. So it almost is a way of

giving them an idea of how to play and communicate with their child in a horrible, frightening situation.

Further to this, the project was described as empowering for wider family members as it can give siblings the power to do something for and with their sibling who is ill and something that health professionals trust and value.

Benefits of the project

Discussions under this theme included benefits for children, families and health professionals.

Child benefits were described in terms of improved health, socialisation and development of social skills, singing skills, musicianship, playing and fun, calming, distraction, improved breathing and lowering blood pressure. The tutors have a value of incorporating each child's name in the songs contributing to children's and families sense of identity through name games:

A dad said to us a couple of weeks ago...a lot of our songs were name games, and we asked him what his name is, and his face lit up and he went oh, I'm normally just dad, and actually to be recognised as a really important person in that child's life rather than just dad, generic. And for the children as well, they're sitting there and they kind of become this patient number, and I think sometimes in the songs you can see their confidence building back up where they regain their identity. The songs are quite often tailored around their likes or dislikes, their tastes or what they're into, and it kind of regains within this quite sterile environment who they are and what they're all about, which feels like it's a really important thing for their wellbeing and their confidence.

There were perceived benefits for **families** in terms of joint participation or time for respite.

There was also thought to be a contribution to staff wellbeing and augmentative health service. It was noted that health professionals like the atmosphere created from singing games generally, although there are exceptions to this for example end of life situations where some professionals prefer quietness. For these situations, the vocal tutors have adapted the singing games to be gentle, calm and appropriate and have sung at several 'end of life' events:

There are occasions when you go onto a ward and they've said, well, they're all asleep, but can you sing to the staff?

The vocal tutors have recently introduced a day where they sing for staff which was appreciated by them:

In August we did an extra day, a special day, on a Thursday, not Friday, and we got as many people in the team as possible to be there, everyone that was available, and we decided that we'd just do singing for the staff and not the children throughout the

day, we'd just go and sing, like a little busking in the corridor or little gifts, we're just here to sing for you. We did a little session in the chapel as well. And when we went to the chapel somebody was going to do a supervision for someone that they line manage, and she said I brought her because she's having a particularly difficult time at the moment so I thought the supervision could be singing today. In the end she came out and said that's better than any supervision I could ever have. I've just sat here and let the singing just pour over me. So that was nice for us to be able to do something for the staff.

There was that one doctor as well who wheeled down the corridor on her chair with a baby on her knee just to sit and listen to the singing.

We went onto Paediatric Intensive Care Unit (PICU) singing carols and I'd been to check where was appropriate, and I thought well, we've got to keyboard, it's probably not going to be on the main ward. So they told us to set up in the entrance hall, next to the desk when you first go in where you wash and down the main corridor, knowing the doors would be open and floods of sound would go down and the doors would close and it wouldn't be too much. And after we'd done one song one of the doctors from PICU came down and said would we go onto the ward please and sing actually on the ward. We thought do we, don't we. Well, we will because they've asked us to. And we sang Away in a Manger, and within the first two phrases the place had gone silent and everybody had just stopped, all the staff had stopped. All you could hear was just the occasional beat, and there was no sound. Normally it's really busy, noisy. And it just, first time ever on PICU I thought wow whilst we were singing. And then gradually one by one they came over and started to sing with us as well. Amazing.

Mapping against FT strategy

In planning the study, there was an objective of providing evidence of how effective practice that follows Froebelian principles can be developed and supported for children in care and education settings (in particular where childhood is under stress and opportunities for children to make choices and engage in playful activities is limited). The Singing Medicine project recognises that even in restricted environments children's right to play and unique capacities and potential can and should be respected and valued. In addition the project recognises the potential of music and singing to promote children's holistic development and children's relationships with family members and other adults such as health and education professionals. The role of play and creativity and children's right to protection from harm as well as promotion of their overall well being are principles that underpin the project. Adult engagement with young children is a crucial element of the research and the project seeks to address disadvantage (health and wellbeing disadvantage) and value diverse family practices and patterns of interaction that are part of the child's health and medical care package. The project maps to Froebel Trust research priority number 4. Developing playful pedagogy and resourcing for play and number 5 finding pedagogies that are inclusive of and celebrate diversity. Participants were asked about the relationship

between the Singing Medicine singing games and Froebelian Principles. Responses of all participants have been synthesised in this section and are discussed below.

1. The integrity of childhood in its own right

The vocal tutors commented that the Singing Medicine project is about playing games and letting children be themselves. A parent also noted that children's right to sing is important and the project promotes that right. One of the professionals highlighted the way in which the Singing Medicine project has intentionality (aims) but that the intentionality is promoted without disempowering children. Another professional suggested that the project brings positivity into children's lives.

2. The relationship of every child to family, community and to nature, culture and society

One parent commented that Singing Medicine has become part of the family and helps to build relationships

From the vocal tutors, the following observations were made and family and community connections:

Children are missing out on music that they might be involved in school or in the family, in the home, in the car, on the way to holiday, bath time or something, so to try and normalise...And I think because a lot of their family are often there...well, siblings during the holiday, but parents are there or aunties or grandparents. It's a way of connecting with their family as well. So it gives them some play and family time, something fun to do together. And the story songs, the children can draw on happy memories for songs, and they can do that as a family.

In 'stem' one little boy who was so poorly, more poorly than I've ever seen him before, and yet he was able to ask his dad to wear Scottish socks within the song, so his dad had to do highland dancing. He did highland dancing despite his son being so ill, and they were both really weary, the parents, but he got up and did the most amazing highland fling. I've never seen anything like it.

Professionals in interviews also mentioned the way in which the project enables children to connect with culture and nature through songs and games when they might not be able to do this otherwise if their treatment requires a long-term stay in hospital.

3. The uniqueness of every child's capacity and potential

The majority of professionals in interviews commented that the project is personalised to each child's capabilities and needs. One professional mentioned that the project helps to change the culture of the hospital by ensuring every child has a choice about something. It was also stressed by professionals that each child is spoken to individually and each child's name is spoken, thereby valuing their identity. All children are included (every child has the opportunity to participate). The vocal tutors made the following observations:

[We are] singing songs that are appropriate for that child at that time. We value each individual - we change the song, we write a new song for them, and we treat them like a person, not a child, it's like we're entering into their childhood, to be part of that childhood rather than leaving ourselves outside looking in.

The vocal tutors commented at length on the different ways and methods they use to value the uniqueness of each child's capacity and potential especially where close observation of the different ways in which children demonstrate this are not necessarily overt:

The first Singing Medicine film we did there's a bit of one child singing can you blink, just like me, and there's this little child blinking, and that was all she could do so that was what she did. I just think that's amazing.

There was a little girl in intensive care who'd been in an accident and she was completely paralysed in a brace all the way up and down, and all she could do was wiggle her tongue and her eyes, and so we did something similar. You always talk about children's capabilities and let's build on that, and that struck me then that well, they can all do something.

We did have an instance where a child had come out of a coma two weeks previously and she'd had an operation, she'd said one thing in two weeks, and we did the picnic song, and her mum was about to sing the answer for her, and suddenly out of the mouth of this child came "Bananas." It does give children the opportunity to speak for themselves and show what they want and what they can do.

Even when we're working with children that do not use speech or blink or move their tongue and are seemingly seem completely asleep, we still adapt what we're doing but we're watching their heart rate monitor. There was a lady whose son was very poorly and who was asleep, when she saw his heart rate going up she got very excited, so she said oh sing some more, keep going.

Every single patient is different. We don't see the same patient type back to back. We go from a 14 year old to a one month old to a nine year old to a six year old to a group to someone who can't do very much at all to someone who wants to do composing. So every single time you go into a bed space you treat it as a brand new day. It's not really related to what you've just been doing.

There's a certain sense of improvisation around it, because yes, we do know quite a lot of the same songs but the way in which we decide to encourage people is completely different every time.

For other children who are actually able to do quite a lot the vocal tutors help them to find outlets for their creativity by for example helping them to use new Apps on their ipad to write music and lyrics. This includes children who may never have written songs before.

4. The holistic nature of the development of every child

A number of parents commented on the holistic nature of music that they thought was good for spiritual and brain development as well as the songs themselves helping children with number concepts and learning colours. Eleven professionals commented on the holistic nature of the Singing Medicine project that augments medical treatment for children. The term 'participative empowerment' was used by one professional to describe the way in which the singing games value children's participation in their hospital life, which serves to empower them.

5. The role of play and creativity as central integrating elements in development and learning.

All of the parents mentioned the contribution that the Singing Medicine project made to children's play and creativity. One parent commented that the vocal tutors are always playful. A number of parents also mentioned the way in which the tutors make up new verses as they go along and encourage children's pretend play involving puppets and other props as necessary. The majority (eleven) professionals commented on the creative nature of the project. The vocal tutors thought that the project was 'making the impossible possible through creativity for example bringing the beach into hospital through songs.'

It feels difficult sometimes. Those moments can often be a bit tricky because we want to take them back to that world, but sometimes I wonder whether it highlights the fact that they're not in that world, and I worry about drawing attention to the fact that they...can't eat solids or might well not have been to the park for two years. So singing about going to a picnic in the park, I don't want to make them sad because they haven't been for a picnic in that long. But at the same time that's probably me just overthinking it being an adult, I don't know. We go to Mars on my picnic so sometimes it can be about moving forward, but sometimes that's why it's good that we do play nonsense and it's about oh, I'd like to be on the moon today or I'd like to be a superhero and my superhero skill is...something that's silly that's completely childhood, imaginative, not limited. I think you have to remember the things that are important, even if it's something you can't do anymore, it's still good to remember isn't it?

The tutors stressed that they are not teaching children a repertoire of songs; the repertoire of songs is the medium through which the singing games engage children in play. Continuous feedback from children (through verbal and non-verbal means) is monitored and an iterative process of adaptation of the songs and games is an important aspect of the project:

We can visit one child one week, never seen them before, sing a song and then do three or four other songs and then go back and see the same child next week. You look in the records and see what songs you've done and immediately start with, say, Picnic, for instance, and they will remember it because we haven't taught it to them, we've just done it, it's part of the game we're choosing, and they just remember the song, they remember how to play. But you know what though, let's say you did the picnic two weeks ago and then G did the picnic last week for the same child, G might do it slightly different, but there's no way that child was like well, no, it goes like this.

It's almost like they're able within this little controlled environment, they're sort of making sense of the world, they're able to reconstruct things themselves or rewrite things or have a power that they haven't got. I don't know, they must do a lot of thinking when they're in those beds. Different type of thinking to how we think about things, I'm sure. I don't know, it's more in the moment isn't it? It's that sense of control, and we're giving them that control but allowing them to be a bit silly as well.

It was also mentioned that musical play is the medium through which children can continue the opportunity to collaborate with peers and communicate through play that they would normally

have in school or other social settings. This is something they would otherwise not have opportunities for during their hospital stay.

6. The right of children to protection from harm or abuse and to the promotion of their overall wellbeing

Four professionals commented that the Singing Medicine project helps to reduce the harm caused by medical interventions. One went further than this saying that it provides moments of freedom:

Participating in the singing games is like taking a child into a meadow and letting them run; getting them into the air and letting them be free. It's a moment of freedom. It's a moment of exhilaration. It's a moment of space, to share, to express, to sing. That's the only way I can, or one way to describe it I suppose. It's almost like being allowed to stretch. (Participant 4).

The vocal tutors made the following observations:

[We are always] assessing the mood they're in to identify whether they need calming, cheering up or distracting.

[The Singing Medicine project] gives children the power to say no – unlike other treatments/services actually as a healthcare professional you can't do that, because you can't say to that child would you like a needle today? I'm really sorry but I have to do this. So I think that's where we here are very different from a lot of the staff.

I think interestingly because the children often are very sick we have to give them the higher status in saying can you hold this beater in your right hand or is your left hand better, and finding nice ways to actually give them the respect, rather than the doctors and the nurses that can come in, they know the medical condition, we have to say do you want to hold it in this one, which one's better, can you wiggle this finger, and they can be in the position they know themselves and they know how they're feeling and they can be in charge of that.

The vocal tutors mentioned the provision of a safe environment created by the Singing Medicine project as well as their cumulative specialist skills as musicians and teachers/health professionals that help to keep children safe. In addition to this, they assess wards and bed spaces to determine children's mood, wellbeing and contextual factors such as equipment and the child's medical state. For example if a child had experienced a car accident then songs that involve language and vocabulary related to cars (i.e. changing gears) would be avoided. Further to this the project provides a distraction from pain and wellbeing from play and signing:

I do remember one time they were trying to insert a cannula into a very tiny baby and struggling, and eventually it worked. It took about 20 or 30 minutes of singing lullabies and calm...so probably 20 minutes. It felt longer. And actually at the end of that the doctor said that would have been worse if you weren't there.

The vocal tutors always visit wards in pairs to ensure safeguarding and they are sensitive to other children in beds close the child they are visiting. Sometimes Social Workers will ask to observe parent/child interactions during a session where parents are attending supervised visits.

The findings from interviews, observations and focus group discussion can accordingly be mapped against Froebelian Principles in the following way:

Froebel principle	Links from findings
Integrity of childhood in its own right	<ul style="list-style-type: none"> • Singing Medicine enables children to be themselves • Singing Medicine promotes children’s right to sing • Singing Medicine intentions empower children • Singing Medicine brings positivity to children’s lives
The relationship of every child to family, community and to nature, culture and society	<ul style="list-style-type: none"> • Singing Medicine helps to build family relationships • The singing games offer a way to connect with family and draw on and create happy family memories • The Singing Medicine project enables children to connect with culture and nature through singing games in a way they might not otherwise do when spending long periods of time in hospital
The uniqueness of every child’s capacity and potential	<ul style="list-style-type: none"> • The Singing Medicine project is personalised to every child’s needs and strengths • Every child has a choice about something • Each child is spoken to individually and each child’s name is spoken – their identity is valued • All children have the opportunity to participate • The vocal tutors work hard to value each child’s capacity and work individually with children of all capabilities across all wards in the hospital • Singing games and songs are adapted through feedback from sessions with children
The holistic nature of the development of every child	<ul style="list-style-type: none"> • Music promotes spiritual and cultural development • Music promotes neurodevelopment • The singing games promote number development and children’s recognition of colours as well as supporting language and vocabulary , socio-emotional and physical development • The Singing Medicine project is holistic in nature and augments medical treatment for children • The Singing Medicine project and singing games empowers children through participation (enables participative empowerment)
The role of play and creativity as central integrating elements in development and learning	<ul style="list-style-type: none"> • The Singing Medicine project contributes to children’s play and creativity • The vocal tutors are playful • The Singing Medicine project promotes children’s pretend play • The Singing Medicine project is very creative • Through singing games, the Singing Medicine project ‘makes the impossible possible’

<p>The right of children to protection from harm or abuse and to the promotion of their overall wellbeing</p>	<ul style="list-style-type: none"> • Singing Medicine helps to reduce the harm from medical interventions and supports medical interviews • Singing Medicine provides moments of freedom • The vocal tutors work hard to ensure that they give children choices, work safely with children and empower children (and families) • The vocal tutors follow hospital infection control procedures very carefully, follow children’s lead, provide opportunities for choice and respect child/family preferences and interests
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Table 3: Mapping Singing Medicine against Froebelian Principles

Discussion

This study aimed to explore the views and perceptions of parents and professionals who care for and support children who participate in the Singing Medicine project delivered at Birmingham Children’s Hospital with a particular focus on children’s wellbeing, right to make choices and engage in playful activities in restricted environments. The study adopted a bio-psycho-social approach that acknowledges the multiple integrative influences on children’s overall learning and development. Twenty participants were involved in semi-structured interviews and three non-participant researcher observations of the Singing Medicine project were undertaken. Following this a focus group discussion with vocal tutors from the Singing Medicine project helped to identify ways in which the findings could be mapped against Froebelian Principles.

Themes that arose from interviews included the important characteristics of the Singing Medicine vocal tutors; contribution to emotions; contribution to child/family experiences of hospital; contribution to children’s development and learning; spiritual and cultural dimensions; contribution to medical care, contextual aspects of the project and contribution to family life, patterns and structures. From observations there was evidence of choices for children; following children’s lead; facilitating medical care; building memorable moments for families and focussing on children’s holistic development.

Findings from interviews suggest that both parents and professionals value the contribution that the Singing Medicine project makes to children’s emotional state during their treatment at the Hospital. This can include helping to calm children, improve their mood or stimulate them where necessary. It can also serve as a distraction which helps to reduce anxiety, pain and stress in relation to medical treatments. Children have a choice whether and how to participate in the singing games and this was perceived as important for and to contribute to their happiness. Furthermore, the contribution to emotions is also beneficial for parents and members of staff at BCH and whilst this is not the primary aim of the project, it has been reported as an important secondary outcome.

Children and families alike were perceived to have an improved experience of their care at BCH if they participated in the Singing Medicine project. This is because the project brings a sense of normality and offers choices and pleasant experiences in the midst of often unpleasant, intrusive

and painful treatments. It was also noted to bring structure to the children's week and offer a way to connect past experiences from home, family and other social settings to their experience in hospital in line with Bronfenbrenner's bio-psycho-social model.

As far as children's learning and development is concerned the Singing Medicine project offers the opportunities for educators to observe children and align observed progress with relevant curricula such as the Early Years Foundation Stage (EYFS) (DfE, 2017). In addition the vocal tutors collaborate with educators to facilitate children's educational targets. Further to this children's participation in the Singing Medicine project was perceived as beneficial to children's holistic development and was thought to contribute to a number of areas of formal curriculum and development domains. An important aspect of this was the way in which the vocal tutors take the time to familiarise themselves with each child's interests and competencies.

The contribution that the singing games make to children's neurodevelopment should not be underestimated. Since children learn and develop in the context of relationships with others, prolonged time spent in isolation or experiences of a high degree of stress, anxiety, pain or discomfort without a distraction or medium to reduce this has the potential to result in resistance to hospital visits and negative neurodevelopmental outcomes. Although Fancout (2017) highlighted the benefit of listening to music for brain development, the participants in the study suggest that the participatory and personalised nature of this project offer something specific to children in Hospital.

An important contribution to children's spiritual and cultural experiences during their stay at BCH was reported by two participants. The manner in which the Singing Medicine project facilitates connectedness between people from diverse socio-cultural-economic backgrounds was noted as well as the sense of achievement and participative empowerment that was enabled by the project which was thought to have positive influences on spiritual and cultural wellbeing.

Medical benefits of participation in the Singing Medicine project were reported in terms of reducing children's heart rates and assisting ventilation. Participating in the singing games was also thought to promote children's neurodevelopment by reconnecting children who were semi-unconscious or children in a state of low arousal to the social world (Bronfenbrenner, 1993). Further to this, the benefits for staff wellbeing that result from observing children experiencing something pleasurable and uplifting were noted. Improvement in the tone of the 'bed space' and calming children/reducing pain were additional benefits as well as providing a means for children with sensory impairments to engage and respond where they might not have otherwise been able.

Contextual aspects of the Singing Medicine project included the appropriateness of its use for end of life situations, particular benefits for children with mental health problems, children who haven't responded to other stimuli, younger/developmentally younger children, post transplant patients, children placed in isolation and not receiving many visitors (where it can provide distraction) and children who need rehabilitation.

The benefits of children's participation in the Singing Medicine project for families and family practices were predominantly related to the benefits for family relationships and joint participation in an enjoyable activity. This was because participation from all family members is encouraged and families can continue to participate in new songs learned through the project together at home. Therefore the project helps to re-build or strengthen family bonds and enables the development of

'happy', 'positive' memories which can be shared together when the child leaves hospital or enjoyed by parents and other family members in the event that children do not recover from their illness. It can also bring happy memories for families of events before their child was ill and provide time and opportunity for parents to have respite during their visit to the hospital should they not wish to participate with their child.

The important characteristics of the vocal tutors who offer the Singing Medicine project are an interesting finding and suggest that important characteristics for vocal tutors to hold are a sense of fun; gentle nature; an inclusive philosophy; happy disposition. The characteristics of the project itself that were perceived as important were educational value; enhancing predictability for children; positive effect on children, families and staff; distraction therapy; entertainment value and a distinct identity for the vocal tutors that makes them easily recognisable (e.g. their purple T-shirts).

Analysis of researcher observations identified that participation in the Singing Medicine project promoted children's ability to make choices about participation and level of participation in a number of ways although this relied on a high degree of vigilance and responsiveness to children's non verbal cues and signals from the vocal tutors. The vocal tutors were also observed to facilitate medical treatment by introducing new actions/verses into singing games that prompted children to shift position enabling health professionals access to particular body areas. There were observable opportunities for families to build memories and family bonds in a fun and enjoyable way. Participation in the Singing Medicine project appeared to offer opportunities for overall child development and children's engagement with the singing games was observed to be high, possibly linked to the attention paid to each child's interests in delivery of the project.

This study included a small sample which limits the potential to generalise the findings, however, the sample was as varied as possible and the findings are relevant to the hospital setting in which the study was undertaken. Further studies with a larger sample and an evaluative aspect would provide a stronger evidence base. In particular, the benefits for children's neurodevelopment demand attention. Further research into children's experiences of the Singing Medicine project would be interesting as well as the emotional impact of delivering the project on the vocal tutors.

The findings can be mapped against all six of the Froebelian principles promoted by the Froebel Trust as shown in Table 3. The project values childhood by promoting children's right to play and relax, whilst at the same time valuing children's interests, identities, capacities as well as medical fragility. The project adopts a family-centred model of operation that values the bonds and connections between children and significant others in their lives. Connecting children to the outside world of nature, culture, community and society through singing games is evident throughout the findings. The central role of play and creativity is transmitted from the playful approaches adopted by the vocal tutors that are infectious and contagious. Protection from harm and promotion of wellbeing is facilitated by the training and character of the vocal tutors as well as the contribution of the singing games to children's sense of happiness and wellbeing.

Conclusion

Participating in the Singing Medicine singing games has been demonstrated in this study to benefit children's well being, right to make choices and engage in playful activities. Findings also suggest multiple other benefits for children, families and professionals at BCH from the provision of the

Singing Medicine project that extend beyond the aims and objectives of this project and beyond those suggested by previous studies. For example the benefits for building memories, family bonds and connections, children's spiritual and cultural wellbeing and education and the important characteristics of the vocal tutors offer new insights into this important augmentative area of health care. Currently the Singing Medicine project is offered one day per week at Birmingham Children's Hospital. This means that only children attending the Hospital on that day are able to participate in the project.

Outputs and publications from the study

Blackburn, C. (2018) (under review) Promoting children's well-being, right to make choices and engage in playful activities in restricted environments through music and singing submitted April 2018 to *Arts and Health*

Blackburn, C., (201) Promoting children's well-being, right to make choices and engage in playful activities in restricted environments through music and singing Collaborative Approaches to Music and Wellbeing Research Leeds University October 2018

Blackburn, C., (201) Promoting children's well-being, right to make choices and engage in playful activities in restricted environments through music and singing National Conference of Senior Children's Nurses London September 2018

Blackburn, C. and the Ex Cathedra vocal tutors (2018) *Promoting children's wellbeing, right to make choices and engage in playful activities in restricted environments through music and singing*. BCU annual CSPACE conference Creativities in Education, Birmingham 3rd July 2018

Blackburn, C. (2018) Promoting children's well-being through music and singing British Education Research Association (BERA) Blog <https://www.bera.ac.uk/blog/promoting-childrens-wellbeing-and-right-to-make-choices-and-engage-in-playful-activities-in-restricted-environments-through-music-and-singing>

Blackburn, C., Ayling, M. N, and Raeburn, H.,(2018) *Promoting children's wellbeing, right to make choices and engage in playful activities in restricted environments through music and singing*. Presentation to Child Health Nursing Team at Birmingham City University 25th April 2018

Blackburn, C. (2018) *Promoting children's wellbeing, right to make choices and engage in playful activities in restricted environments through music and singing*. Parallel Session at BECERA Annual Conference, The Mac, Birmingham 20th February 2018

Blackburn, C. (2018) *Promoting children's wellbeing, right to make choices and engage in playful activities in restricted environments through music and singing* BCU CSPACE Blog <http://blogs.bcu.ac.uk/education/2018/02/14/promoting-childrens-wellbeing-right-to-make-choices-and-engage-in-playful-activities-in-restricted-environments-through-music-and-singing/> 14th February 2018

Blackburn, C, Leddgard, R., Toumi, M. Raeburn, H., King, G. Weber, U., Spencer, S. and Budd, S. (2018) *Promoting children's wellbeing, right to make choices and engage in playful activities in*

restricted environments through music and singing. Workshop at Birmingham City University
Annual Health Conference 'Creative Caring', 24th January 2018

References

- APPG on Arts, Health and Wellbeing (2017a) Policy Briefing *Arts Engagement and Wellbeing* July 2017 [Online <http://www.artshealthandwellbeing.org.uk/appg-inquiry/> accessed 11.12.17].
- All-Party Parliamentary Group on Arts, Health and Wellbeing (2017b) *Creative Health: The Arts for Health and Wellbeing* [Online <http://www.artshealthandwellbeing.org.uk/> accessed 12.12.17] .
- Bronfenbrenner, U. (1993). The ecology of cognitive development: Research models and fugitive findings. In R. H. Wozniak & K.W. Fisher (Eds.), *Development in context: Acting and thinking in specific environments* Hillsdale, NJ: Erlbaum. pp 3-44.
- Bronfenbrenner, U., (2001) The bioecology theory of human development. In N.J. Smelser and P.B. Baltes (Eds) *International encyclopedia of the social and behavioural sciences* 10 pp 6963-6970.
- Elkind, D. (2015) *Giants in the Nursery. A Biographical History of Developmentally Appropriate Practice*. St Paul, MN: Redleaf Press.
- Engell, G. L., (1977) The need for a new medical model: a challenge for biomedicine *Science* 08 Apr 1977: Vol. 196, Issue 4286, pp. 129-136 DOI: 10.1126/science.847460
- Fancourt, D. (2017) *Arts in Health, Designing and Researching Interventions*. Oxford: Oxford University Press.
- Hallam, S. 2015. *The Power of Music: A Research Synthesis of the Impact of Actively Making Music on the Intellectual, Social and Personal Development of Children and Young People*. London: Music Education Council.
- Lamont, A. 2008. "Young Children's Musical Worlds: Musical Engagement in 3.5-Year-Olds." *Journal of Early Childhood Research* 6 (3): 247–261.
- Lerner, R. M. 2005. "Foreword: Urie Bronfenbrenner: Career Contributions of the Consummate Developmental Scientist." In *Making Human Beings Human: Bioecological Perspectives on Human Development*, edited by U. Bronfenbrenner, ix–xxvi. Thousand Oaks, CA: Sage Publications.
- Lonie, D. 2010. *Early Years Evidence Revue: Assessing the Outcome of Early Years Music Making*. London: Youth Music.
- Powell, S. & Goouch, K. (2015) *Principled Encounters in Daycare for Babies: Froebel's Legacy*. London: The Froebel Trust. www.froebeltrust.org.uk.
- Spratt, J. (2012) The importance of hand and finger rhymes: a Froebelian approach to early literacy pp. 95-106 in T. Bruce (ed.) *Early Childhood Practice. Froebel Today*, London: Sage.
- Williams, K.E., Barrett, M.S., Welch, G.F., Abad, V. and Broughton, M. (2015) Associations between early shared music activities in the home and later child outcomes: Findings from the Longitudinal Study of Australian Children. *Early Childhood Research Quarterly* (21 (2015) 113-124.
- Young, S. 2007. "Changing Tune: Reconceptualising Music with Under Three Year Olds." *International Journal of Early Years Education* 13 (3): 289–303.

Young, S. 2008. "Lullaby Light Shows: Everyday Musical Experience among Under-Two-Year-Olds."
International Journal of Music Education International Journal of Music Education 26 (1): 33.

Appendix 1: Details of participants (in order of interview dates)

Name	Job title	Age	Length of time working at BCH	Description of children working with
Interview 1	Play facilitator role involves normalising play	26	Ten months	Zero to seven but mostly zero to five – specialised medicine – anything from gastro problems to bronchiolitis, failure to thrive, neuro problems
Interview 2	Research Nurse Co-ordinator, Intensive care research trialling a new wireless monitoring system	40	Fifteen years	Birth to 16 with cardiac defects, having cardiac surgery or just under the cardiology team
Interview 3	Mother to seven year old C who has acute myeloid leukaemia	38	n/a	n/a
Interview 4	Family Liaison Nurse	27	Four and a half years	Wide range of children from cardiac, trauma, respiratory, children who are ventilated, intubated and experience short term and long-term stays
Interview 5	Clinical lead nurse (PICU)	50	Six years	Birth to sixteen (sometimes 18), caring for the sickest children

				in the hospital / country – in the largest PICU in Europe
Interview 6	Sister Haemodialysis Unit	55	Twenty years	Birth to eighteen - Children are categorised by weight because renal failure limits growth – so four kilos to 70 kilos
Interview 7	Mother of a child who attended the Singing Medicine project who died in 2015 aged twelve	42		
Interview 8	Chaplain	53	Eleven years	All children, families and staff in the hospital
Interview 9	Physiotherapist	26	Twelve months	Children aged birth to eighteen across a range of wards
Interview 10	Senior Chaplain	57	Fifteen years	All children, families and staff in the hospital
Interview 11	Play worker	Twenty-five	Eighteen months	Children aged seven to sixteen years (occasionally up to eighteen years)

Interview 12	Consultant paediatrician interventionist	Thirty-nine	Seven years	Specialist children's intensive care for children aged birth to eighteen
Interview 13	Play worker/family support worker	Thirty-seven	Five years	Children aged birth eighteen on the intensive care unit
Interview 14	Adult who participated in the Singing Medicine project as a child	Eighteen		
Interview 15	Mother of a three year old child who has renal failure	Thirty-three		
Interview 16	Sibling of a patient on the oncology and haematology ward who is fourteen years old	24		
Interview 17	Consultant paediatric liver specialist	49	Thirteen years	Children aged birth to eighteen who are treated on the liver unit
Interview 18	Teaching Assistant	50	Nine years	Works in the school on site on the oncology unit on a one-to-one basis with children aged four to eleven years who have cancer or

				leukaemia
Interview 19	Mother of a seven year old child who is a long-term patient on the oncology ward together with her child and a translator (mum and daughter are Albanian and newly arrived in the UK)	Preferred not to disclose her age		
Interview 20	Mother of a four year old who has leukaemia	20		

Appendix 2: Description of dialysis from participant 6

It's a long time for a two year old or a three year old, even a five year old, and they get so bored. So we have the teachers come in, we have a play worker there, play specialist and stuff, but it's just so mundane sort of sitting there, and then obviously the teaching staff have got to focus on academia as well because they miss so much of school, especially the smaller ones. The bigger ones do go to school an awful lot, so they have three full days and two half days of school.

Whereas, the little ones, say, if they're in reception or whatever, they're missing a good chunk of their school so, for example, they come in and they get on the machine. It takes about half an hour, 20 minutes, to do their blood pressures, their weights and everything, before they get on the machine and then they have to lie quite still, they have to have plasters taken off, which is not nice, and they have to have their dressings done once a week, which is not nice either, that can be quite painful.

The actual dialysis itself is not painful because we attach the tubes to their lines, so they have a big central line in their body, so we attach the lines on the machine to their lines. So, in theory, it's not supposed to be painful, that part of the procedure, but they still have to lie still and they can't touch our hands, they can't move around. Then they have to lie close to the machine, because they're so small it's quite different from adult dialysis, the lines are quite short, and so they can't jump around or do anything, basically, just in case their line comes out anyway.

Then, also, what we have to do is we clean their blood. So the blood goes through a dialyser and it gets filtered of all the impurities and, apart from cleaning their blood, we also take fluid off them so we can make them feel unwell. Then, with small children, they can't express how unwell they feel, so if we take the fluid off too quickly they can feel unwell, but a two year old feeling unwell...an adult or a bigger child will say, I've got a headache, or, my stomach hurts. A two year old won't, so they'll end up crying and those sorts of things, or their heartrate will go up.