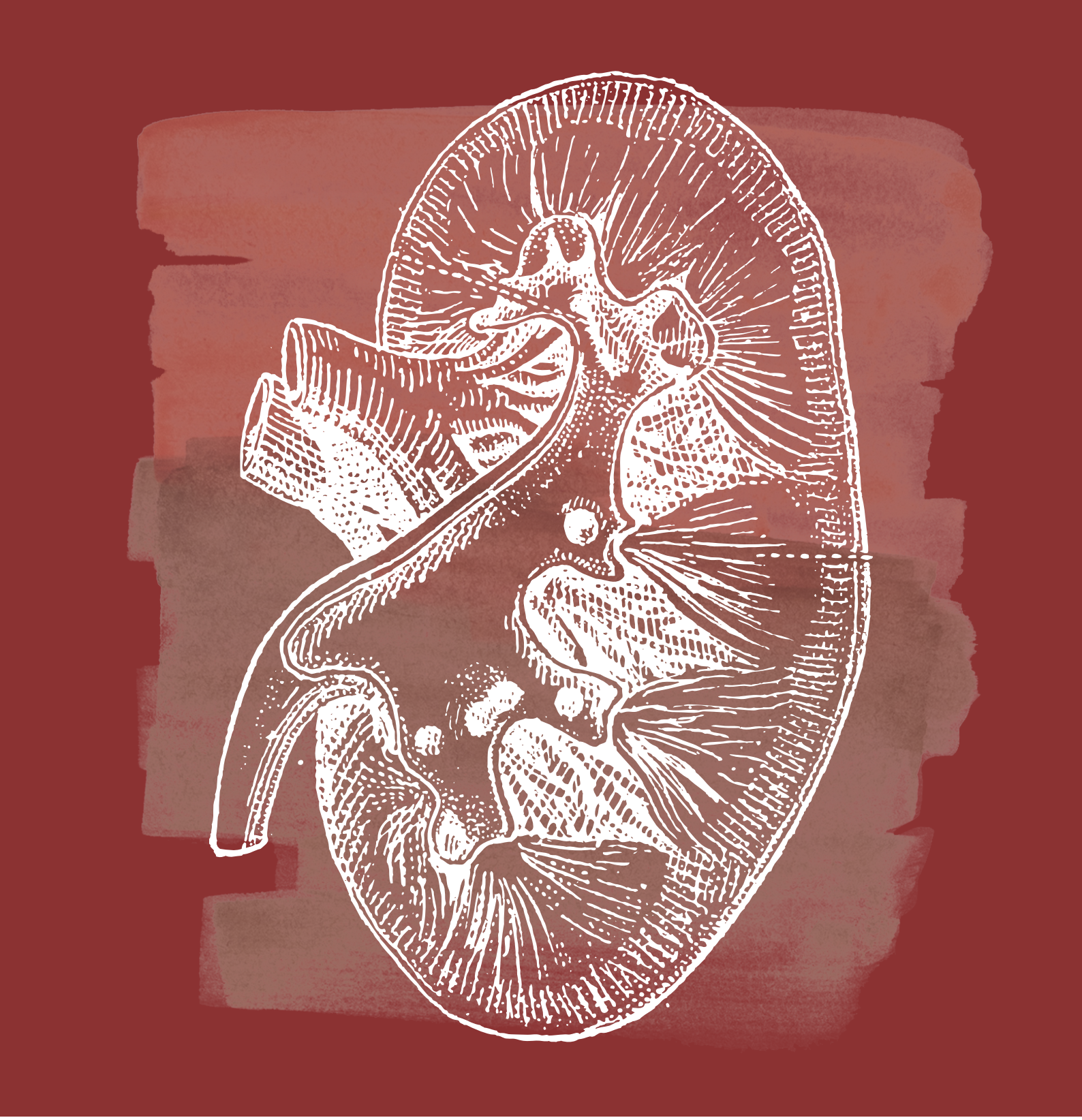

RENAL ARTS GROUP

GUIDANCE ON IMPLEMENTING VOLUNTEER-LED INTRADIALYTIC ARTS ACTIVITIES IN HAEMODIALYSIS UNITS.

Economic and Social Research Council
Northern Health and Social Care Trust
QUEEN'S UNIVERSITY BELFAST
Renal Arts Group
Improving quality of life through art

GUIDANCE ON IMPLEMENTING VOLUNTEER-LED INTRADIALYTIC ARTS ACTIVITIES IN HAEMODIALYSIS UNITS.

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INTRODUCTION

Haemodialysis

Haemodialysis is one of the main forms of treatments for patients with kidney failure. It involves attending hospital three times a week for four hours each time. During these visits patients are confined to a bed and are connected to a dialysis machine, typically through two needles that are inserted into their arm. Over the course of four hours the patients' blood is drained from their body and fed through a machine called a dialyser. The dialyser filters their blood, removing excess fluid, waste, and balanced electrolytes, replacing the role of the damaged kidneys. This treatment is life-sustaining, meaning the patient has to attend these thrice weekly appointments either until they have a kidney transplant, or for the rest of their life.

Whilst connected to the dialysis machine patients have limited opportunities to engage in meaningful activities. The majority of patients try to sleep, watch TV, or read, but most patients experience a profound sense of boredom, with little to fill the time whilst undergoing this treatment, and experience time passing very slowly. In the academic literature this boredom is described as 'existential boredom', because patients typically dwell on thoughts of the past, their illness and poor health, and death. As a result of this patients are at an increased risk of developing mental health issues such as anxiety and depression.

Arts on Dialysis

The use of arts in health has come to the recent attention of the public as a result of the All Party Parliamentary Group for Creativity and Well-being report in 2017, which highlighted numerous different ways that art could be used to support patients, the national health service and the general public. Additionally, the World Health Organisation published a scoping review in 2019 exploring the varied evidence base on the use of arts to improve health and well-being. While there was a wide range of examples of research being undertaken in the field of arts and health, there were no studies identified that explored the use of arts in renal settings.

Despite this lack of research, there are a number of reasons why the arts are particularly well placed to address the issue of empty time and boredom for patients receiving haemodialysis. Arts induce a subjective experience called a 'Flow state', a mental state people enter when they are completely absorbed in an activity. The hallmark experience of a Flow state is an altered perception of time, most typically people experience time passing a lot more quickly than it actually is. Consequently, the opportunity of inducing Flow states for patients receiving haemodialysis could be a valuable tool to address the psychological consequences of a difficult and time-consuming treatment.

Feasibility study

Other potential benefits of the arts were identified through a feasibility study conducted in the Northern Health and Social Care Trust between 2018 and 2019, in an attempt to address the lack of evidence for the use of arts in haemodialysis settings. Whilst the arts-based intervention that was delivered during this feasibility study was designed to induce a state of Flow, interviews with participants revealed that the intervention had further reaching benefits than originally anticipated.

The main benefits described by patients during the interviews included:

- Increased self-esteem
- Development of a sense of purpose
- Feeling happy
- Increased social interaction

The feasibility study also found benefits for the healthcare professionals who worked on the unit where the arts-based intervention had taken place, including improved communication with patients. Whilst the study was not designed to establish a cause and effect relationship or explore the impact of the intervention on clinical outcomes, it did provide insight into the potential of the arts in this unique clinical setting.

Although the feasibility study was conducted to evaluate the potential of conducting a large randomised controlled trial, the success of the study and the arts-based intervention resulted in the need for a separate strategy, focused on more immediate provision of the arts in the Renal unit. Therefore, this guidance will outline a strategy for sustained provision of the arts within a haemodialysis unit using volunteer facilitators.

AIMS AND OBJECTIVES

Aim: Develop guidance on developing a volunteer-led arts programme within a haemodialysis unit.

Objectives:

- Outline the format of the arts programme to be delivered in a haemodialysis unit, in a manner that will allow easy understanding and replication for volunteers.
- Provide a description of the volunteer role within the trust.
- Identify key training requirements for volunteers and how these can be facilitated.
- Identify recruitment strategies for volunteers and how these can be maximised to promote engagement
- Establish key governance and standards considerations for implementation.

WHY VOLUNTEERING?

The most typical approach to arts in health programmes is the provision of discrete arts activities that are facilitated by professional artists who are employed as artists in residence. Whilst this approach ensures that the arts are directed by someone with professional training and thorough knowledge of the arts, it limits the pool from which facilitators can be recruited. The arts-based intervention that was developed and implemented within the feasibility study involved facilitation by the primary researcher, who was a trained mental health nurse but had no higher arts education. The success of this facilitation further suggests that a professional arts qualification is not necessary for engagement. Additionally, some of the most important aspects of facilitation that was identified from the feasibility study were good communication and interpersonal skills, suggesting that professional arts education may be less important when it comes to sustained engagement from patients.

The nature of the proposed arts programme also differs in nature to the typical role of an artist-in-residence. Artists-in-residence tend to place less of an emphasis on the development of artistic skills amongst patients within a hospital, mostly due to practical constraints of the role. The development of artistic skills requires regular, sustained direction and practice, while artists-in-residence have finite time for each individual project and therefore focus on collaborating with patients to create large artistic pieces for display within the hospital.

The focus of the arts-based intervention that was developed for the feasibility study focuses on skill development over the creation of final pieces of art. This focus on skill development was closely aligned with the theoretical framework of the intervention and contributed to the positive experiences of participants in the feasibility study. A sustained volunteer programme would allow volunteers to support patients within a haemodialysis unit to develop skills over longer periods of time, placing less of an emphasis on the aesthetics of produced artwork, and more emphasis on the learning experience. Therefore, the role of volunteers and artists-in-residence are distinct, with volunteers supporting the work of artists-in-residence.

SARS-COV-2 PANDEMIC

In December 2019 a cluster of pneumonia cases in Wuhan, China, were identified as being caused by a novel coronavirus, eventually named SARS-CoV-2. During the first three months of 2020 the virus had attained a global spread and a pandemic was declared by the World Health Organisation. As a consequence of the pandemic numerous countries took a variety of different measures to manage to the spread, reduce transmission and attenuate the pressure being placed on healthcare systems. On the 23rd of March 2020 the United Kingdom announced a nationwide lockdown, and a number of strict social distancing measures were implemented to ensure the safety of people who would be particularly vulnerable to effects of the virus, including those with end-stage kidney disease.

The development of this guidance commenced in March 2020 and was originally conceptualised as involving the provision of direct one-to-one bedside facilitation of intradialytic arts activities. However, due to enhanced infection control protocols within hospitals and Renal units, and risk management strategies employed by health and social care trusts, this approach to delivery would not be feasible within the foreseeable future. As a consequence of this the guidance has been developed based on a blended approach, simultaneously describing a strategy for the provision of arts within the restrictions of the current SARS-CoV-2 pandemic, and an additional strategy for more sustained direct provision following the pandemic, that had been originally planned utilising the original approach used in the feasibility study.

ARTS PROGRAMME

A manualised version of the art programme is included in Appendix 1. The type of provision will depend on the access the volunteer facilitator will have to the haemodialysis unit, as there may be enhanced infection control and restrictions as a result of the pandemic. The following are the key differences and considerations for each type of provision:

Remote provision

- There will be additional barriers for certain patients, in particular those with arteriovenous fistulas, to engage in the arts through remote provision. This will influence what patients can be invited to participate in this phase of implementation. Due to the lack of one to one attention it may be difficult for patients who have mobility restrictions in their upper body, for example patients who have an AVF in their
- dominant arm, or patients with extreme fatigue, to engage due to their need for direct practical support. This should always be gauged by the patient's comfort level, and if a patient expresses a desire to engage they should not be dissuaded unless there is a clinical concern.
- Patients are provided individual arts pack, including sketchbook, pencil, eraser and sharpener. The patients will need to retain ownership of these arts pack and the pack cannot be stored on site, to ensure the risk of cross-contamination is kept to a minimum.
- Patients will be invited to participate in the programme through the artist-in-residence, advertisements within the unit and/or healthcare professionals who will act as advocates for the programme.
- The volunteer facilitator will be matched with a patient, and will make initial contact to arrange the first session and provide an outline of the programme. The emphasis should be placed on the ability of these activities to help patients pass time and alleviate boredom, as while they may seem trivial, these are issues that are of high concern to patients receiving haemodialysis.

- Volunteers will provide one-to-one facilitation over video calls. Their role will be to provide encouragement and motivation, guidance on artistic techniques and skills, and contact to promote engagement and the development of artistic skills over time.
- Pre-recorded online tutorials can be used to help support the virtual one-to-one sessions provided by the volunteer facilitator.
    - The videos on their own, without any form of direct facilitation or guidance, will likely not result in a sustained response from patients in the unit, therefore consistent input from volunteer facilitators will help motivate and engage patients.
- When there are enough participants in a single dialysis shift they can be organised into a single bay for enhanced social engagement. This will depend on the practicalities of the clinical setting and patient preferences.

Direct provision

- Direct provision utilising one-to-one facilitation at the patient's bedside was initially planned prior to the SARS-CoV-2 pandemic and the implementation of stricter infection control and social distancing protocols. This form of provision is based on the complex arts-based intervention developed by Carswell et al. (2020) and implemented as part of the feasibility study.
- A broader range of patients will be able to engage in direct provision due to the fact one-to-one facilitation promotes accessibility through practical support and assistance with the arts materials. Therefore, patients with AVFs, AVFs in the dominant arm, patients with limited upper-body mobility and those in isolation will likely be more comfortable participating in this form of provision.
- The initial recruitment and introduction of patients to this direct art programme should be conducted by the individual who is going to provide the one-to-one art sessions, for example, the volunteer facilitator. This will allow patients to voice any concerns, ask questions and for the volunteer to cater their sessions to the personal interests and skill level of the patient who is taking part.
- Similar to the remote provision, each patient will also be provided an individual arts pack, including essentials such as a sketchbook, pencil, eraser and sharpener. This will alleviate any concerns about infection control and cross contamination in the clinical setting, and will also enable patients to engage outside of the set sessions provided within the unit. However, due to the additional practical support, a wider variety of arts materials can be provided.

VOLUNTEER ROLE DESCRIPTION

(Based on the activity volunteer description within the Northern Health and Social Care Trust)

Department/base: Home based (remote provision)/ Renal unit (Direct provision)
Reports to: Supervisor (TBC)
Responsible to: Service manager
Volunteer role summary: As an activity volunteer volunteers can expect to assist staff with activities that will support service users in the development of their own health and wellbeing. Some of the roles of the activity volunteer can include: Arts & Crafts, music.

Main activities of an activity volunteer:

- To attend the department or provide virtual / telephone support at the agreed time and ensure that information and any support materials are available for the duration of the volunteering activity.
- To wear the Trust ID and any other identifying lanyard or uniform
- To proactively engage with attendees to the department whilst respecting the rights of those who do not wish to engage.
- To identify and meet identified information and support needs which may include referral to others as agreed.
- To attend Trust wide and departmental induction, any agreed training and support and supervision sessions with the volunteer supervisor

- To inform the volunteer supervisor of any concern/compliments or issues requiring their attention.
- Where the volunteer is unable to attend for the agreed time to inform the Volunteer Supervisor (or department) at the earliest possible opportunity.

General responsibilities
Volunteers with the Trust are required to promote and support the mission and vision of the service which they help to deliver and:

- At all times provide a caring service and to treat those with whom they come into contact in a courteous and respectful manner
- At all times demonstrate practice which reflects the HSC Values of compassion, openness and honesty, working together and excellence.
- Carry out their activities in a manner which assures patient and client safety
- Comply with all instructions in regard to Infection Prevention and Control
- Demonstrate their commitment by their regular attendance and the efficient completion of all activities agreed with them.
- Comply with the Trust's Smoke Free Policy
- Carry out their agreed activities in compliance with health and safety policy and statutory regulations
- Adhere to equal opportunities policy throughout the course of their volunteering role within the trust
- Ensure confidentiality and security of trust provision
- Ensure the on-going confidence of the public in service provision
- Comply with the Code of Behaviour and terms and conditions outlined within the volunteer agreement

Settling in period
The settling in period will be agreed with your supervisor on the first day of your volunteering. After the agreed timescale you will receive your first review meeting

Out of pocket expenses
The volunteers are entitled to reimbursement of out of pocket expenses as detailed in the volunteer policy. The volunteer supervisor will agree the scale of expenses which the volunteer can claim as part of the volunteer's induction.

TRAINING REQUIREMENTS FOR VOLUNTEERS

(Based on volunteer training requirements within the Northern Health and Social Care Trust)

Direct provision

All volunteers undergo an induction programme consisting of Volunteer Welcome & Induction Training, a Role Specific Induction Programme for Voluntary Placement and any additional training required before commencement of their volunteering role.

Volunteer Welcome & Induction Training includes:

- Introduction to the Trust
- HSC Values for All
- Safeguarding
- Infection Prevention and Control
- Fire Safety
- Information Governance including Confidentiality
- Role and Responsibilities of a Volunteer & the Trust

Due to the specialist nature of this voluntary role and the clinical setting, volunteers will likely need enhanced training. Specifically, this training will relate to the provision of arts and the haemodialysis setting itself.

Remote provision

Volunteers who are providing the arts activities remotely will still undergo the general Volunteer Welcome & Induction Training, however they will not receive training on Infection Prevention and Control, or Fire Safety.

VOLUNTEER RECRUITMENT

Volunteers should be appropriately matched with the role, and not everyone who approaches the trust to volunteer will be matched with their preferred role. Therefore, it is important to have a clear role description, out lined on page 4, and identify any specific skills or traits that are desired for the position. In general it is recommended that interpersonal skills are prioritised over specialist arts training.

In the event that active volunteer recruitment is needed a targeted approach can be taken to enhance the likelihood of recruitment, as well as recruiting individuals with the correct skill set and personality type. For example, targeting students may be a particularly effective recruitment strategy, for example students studying arts and design, English literature, or social or health sciences. Additionally, people with experience of kidney disease may be interested in volunteering, so recruitment could occur through patient organisations. The opportunity can also be advertised internally within the trust and through organisations like Volunteer Now, local volunteer centres, and social media for maximum reach.

SUPERVISION

The responsibility for supervision of volunteers ultimately lies with the Service Manager, who can nominate a team member to take on this responsibility providing they have capacity to do so. Supervision can also be undertaken by a partner organization, and support can be provided within the trust.

Remote provision

During remote provision the Service Manager can determine who would be best placed to supervise a volunteer remotely. As remote provision will not involve the presence of the volunteer within the unit, it is not necessary that the supervisor is on site. Therefore, the supervisor could be a member of staff from the healthcare team, but supervision could also be provided by the artist-in-residence. However, as the supervisor will also be involved in coordinating contact between the patient and volunteer it is important that they also have close contact with the renal unit if they are not a member of staff.

Direct provision

During direct provision volunteers will require a named supervisor on site, ideally a member of the healthcare team. The volunteer co-ordinator of the trust will be able to support the supervisor in their role and any necessary training can be sourced, for example supervision training provided by Volunteer Now. The supervisor in this instance doesn't necessarily need a highly level of artistic proficiency, but instead is there to support the volunteer in the haemodialysis setting, and additional support for any arts training needs can be sourced through voluntary arts organisations working within the trust.

GOVERNANCE AND FUTURE CONSIDERATIONS

Future considerations should focus on two core streams, continued and sustained provision of volunteer-led arts activities within Renal units across Northern Ireland and the establishment of an evidence base to demonstrate impact through research that has the capacity to inform policy

Sustained provision in Renal units across Northern Ireland

The ability to sustain provision of the arts in Renal units across Northern Ireland will depend on a number of different factors, including funding, support from HSCT, support from Renal units, and patient engagement.

Funding

Funding is necessary to provide the arts materials for the individual arts packs that will be provided to patients, as well as reimbursements for the out of pocket expenses of each of the volunteers. Some haemodialysis units may have charity funds available within the trust, and alternative funding could be applied for through both local, regional and national charities and patient groups such as kidney patient associations, Kidney Care UK, or other community organisations.

Support from the HSCT

This guidance has been developed in conjunction with the Health and Wellbeing Team and Volunteer Co-ordinators within the Northern Health and Social Care Trust in Northern Ireland. The input of the trust has been instrumental to ensuring the infrastructure and support for the volunteering strategy is in place, and that the planned arts provision is in line with trust guidelines. Whilst the feasibility study involved working closely with the research and development arm of the trust, a broader view has to be taken when implementing more sustained provision. Involving clinical service managers, community well-being managers, volunteer co-ordinators, arts in health managers, arts in health providers, infection control and prevention teams, and management within the Renal unit itself, is essential when establishing a volunteer led arts programme.

Support from Renal units

A crucial aspect of sustained provision is support from the healthcare professionals working on the Renal unit. The successful implementation of the arts-based intervention during the feasibility study was dependent on the low level of burden it placed on nursing and care staff during haemodialysis shifts, the ability of the facilitator to work flexibly around routine nursing care and their prioritisation of the clinical environment. If the arts provision places any undue stress on healthcare professionals, or in any way impedes their ability to provide clinical care, provision of the arts in this setting is not acceptable.

The intervention that was developed as part of the feasibility study involved healthcare professionals in the development process, and was able to address any concerns relating to practice and the clinical setting prior to delivery. Consequently, to ensure support from nursing teams within Renal units it would be recommended that delivery closely align with this intervention, outlined in the Appendix.

Patient engagement

The main determining factor of successful implementation of the arts within the Renal unit will be the engagement of patients themselves. If patients do not participate in, enjoy, or see the benefit in the arts activities then provision will not only be unsuccessful, but will be unnecessary.

To promote patient engagement the arts provision will need to have a consistent person-centred and individualised approach. While this will be difficult in the initial introductory stages of remote provision, where there will be a reliance on technology and standardised videos, the use of virtual volunteering will hopefully be able to address this need by providing patients with a point of contact who can tailor support and guidance based on their needs and interests. A person-centred approach is feasible during direct provision, as was demonstrated in the feasibility study, and was shown to positively promote patient engagement and sustained participation. The manualised version of the intervention, attached as an Appendix, provides guidance on how arts sessions can be approached to tailor it to the individual, whilst simultaneously ensuring that each patient receives a similar experience.

The display of completed artwork is a method through which engagement could be enhanced, and initial anxiety over ability could be addressed. Artwork from the feasibility study has been used on social media and during presentations to academics and healthcare professionals as a way of promoting the use of arts in this setting, highlighting the ability of patients to develop their skills and creativity. However, to assuage any anxiety there should not be any requirement or expectation on patients to display completed work if they are not comfortable, and it will be best to provide this opportunity when they have created a number of pieces that they are personally proud of. The Renal Arts Group at Queen's University Belfast is currently undertaking work to develop online resources that could be used to promote engagement during remote provision, when display of artwork is less feasible due to hospital and trust restrictions around infection control.

Patient champion:

- A patient champion can be identified from the initial cohort of patients who engage in the volunteer led programme. This champion should be a patient who is enthusiastic about the initiative and believes that the arts have the potential to improve the patient experience during dialysis. This champion can act as a point of contact for other patients who are interested in getting involved, who can speak to their own experience of intradialytic arts activities and promote them within the unit in collaboration with the healthcare staff and volunteers.

Establishment of an evidence base

Programme evaluations

Regular evaluation of any arts in health practice is necessary as a quality improvement measure, to develop and promote good practice and to demonstrate impact while the empirical evidence base develops.

Consequently, the described volunteer programme should be regularly evaluated once implemented, utilising patient, volunteer and healthcare professional feedback in the form of brief surveys, questionnaires and qualitative components such as interviews and focus groups. Drawing on rigorous research methods to evaluate programmes can add to the evidence base and provide robust justification for continued resources and funding. Consulting and collaborating with academics in University departments is one option for bolstering the quality of evaluation.

Randomised controlled trials to establish efficacy

An application for a Health Technology Assessment grant from the NIHR, to conduct a cluster randomised controlled trial of an arts-based intervention for patients receiving haemodialysis is currently being drafted, with the hope that this can evaluate the impact of intradialytic arts on the mental wellbeing and mental health of patients. Randomised controlled trials are important in the context of the National Health Service as this is the type of evidence used when policy makers recommend resources or allocate funding during the commissioning process. While there is debate in the field of arts and health on whether this is an appropriate methodology, and whether it is the responsibility of the arts sector or the health sector to provide support and funding for the arts in healthcare settings, arts in health programmes have repeatedly had funding and resources pulled due to the inability to refer to a rigorous, quantitative evidence base. Therefore, to ensure access and provision in the long term, this evidence base is necessary.

Scoping / Mapping practice

Despite the lack of an empirical evidence base on efficacy of arts-based interventions, there is ongoing practice of arts in haemodialysis settings nationally and internationally. However, these pockets of practice are disconnected, and there is a lack of awareness of what is occurring in different units across the UK, and how these are being implemented, funded and evaluated.

In order to develop a more comprehensive understanding of arts practice in haemodialysis units a mapping study is necessary to ensure that examples of good practice and novel techniques are not lost to the wider renal community.

References:

Protocol paper for the original feasibility study:
Implementing an arts-based intervention for patients with end-stage kidney disease whilst receiving haemodialysis: a feasibility study protocol

Results of the original feasibility study:
A mixed-methods feasibility study of an arts-based intervention for patients receiving maintenance haemodialysis

Development of the arts-based intervention, including manual on how to deliver the intervention:
Development of a complex arts-based intervention for patients with end-stage kidney disease whilst receiving haemodialysis