

BLOOD

MAKES

NOISE



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EVALUATION

By Anna Ledgard

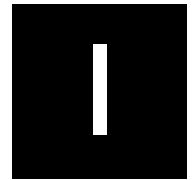
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WATCH BLOOD MAKES NOISE AT

www.mypockets.co.uk/bloodmakesnoise.htm

INTRODUCTION



1.1. Context

Dorset County Hospital (DCH) has a vibrant arts programme. Chronic kidney disease (CKD) has a deep impact on family life and patient ability to lead full and productive lives and so, in consultation with renal consultant and dietitian, a creative project was devised by Arts in Hospital coordinator Alex Coulter with artist/film-maker Peter Snelling. Having been inspired by For the Best, a project in renal wards in Liverpool and London created with Anna Ledgard/Mark Storor (Walsh, 2011) the team wanted to devise a participatory arts process which engaged patients directly in making a film and built patient, public and staff understanding of living with renal illness. The project was to have a special focus on the relationship between diet and renal disease. The arts were seen by both clinician and dietitian, not only as a way of engaging patients in self-expression, but additionally as a means of addressing the difficult and emotionally charged area of patient behaviour around diet and fluid intake. Funding was successfully raised from the British Kidney Patient Association (BKPA) and the Wellcome Trust. The project met Wellcome Trust aims to support collaborations between areas of bio-medical science, the arts and education, and to build public understanding of one of its identified challenge areas: chronic disease.

1.2. Methods

The project began with a 6 month arts residency with a group of dialysis patients attending the renal unit three times weekly and Peter Snelling involved patients in: film-making; an on-line blog; designing renal friendly recipes with local chef Jyoti Fernandes; and evenings of shared cooking and eating. Over the 6 months Snelling worked for half a day a week with 5 patients, visiting homes, interviewing family and friends, and filming 2 patients' journeys from dialysis to transplant operation. Snelling filmed without crew, encouraging participants to use flip cameras or phones, thus enabling them to participate fully. A wider group of renal patients in satellite units in Dorset also took part on-line, building a collective response to films, blog, and food activities. The project participants and their families fed into the film's editing process and contributed to the publication of a recipe book which has been distributed to renal units in Dorset.

Screenings of the film to date include: DCH (March 2013); Bristol Culture, Health and Wellbeing international conference (June 2013); British Renal Society networks (March 2013); dialysis satellite units in Bournemouth and Poole (September 2013). A wider programme of dissemination, using the film and recipe book, is being devised by Dorset County hospital renal dietitians.



EXECUTIVE SUMMARY & CONCLUSIONS

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The key aims and objectives of the project were largely met. Particular strengths were the strong relationships between hospital and artist; the quality of patient engagement with artist; increased sense of community on the renal ward; positive responses and feedback to the film from general public and clinicians; the realisation of plans to use the film as a teaching resource; the involvement of a food producer with renal patients and their families; the production of renal friendly recipe book for wider use and some evidence of improved dietary management resulting in better phosphate results within the target group. The use of blog and online engagement with renal units was less successful and worked best when provoked by direct contact with artist or nurses. The project raised a number of issues which may be of interest to the wider community of artists working in health settings.

This project was rooted in strong and trusting relationships at many levels: artist with patient; staff and dietitian with artist; arts coordinator with hospital managers; renal team with artist and arts coordinator. This was clearly made easier because relationships were initially brokered by the arts coordinator who had a high profile and status within the hospital. The hospital's ongoing commitment to developing health outcomes through arts participation makes it likely that activities initiated in this initiative will be sustained beyond the life of the project.

The conversations between artist and patient over time provided a unique space for self-expression. Patients described their enjoyment of this process and the increased confidence this gave them to be more open about their illness with work colleagues and family. The 5 patient stories demonstrate high degrees of patient autonomy, which is not the norm for renal patients. Their generous contributions have contributed to an authentic film which will build understanding in the wider community as well as providing inspiration to others about living positively with renal illness. The films are both a moving testimony to the 5 patients who were involved, and also a useful resource for hospital educators and others who are using them to involve the general public and new renal patients with issues surrounding diet and lifestyle, as well as social, psychological and ethical issues surrounding organ donation.

The film-maker's emerging definition of himself as 'artist' offers insights into the definitions of this role within a non-arts space, such as a hospital, acknowledging the importance in this practice of reciprocal relationship-building and arts-making which responds to participant contributions and content and cannot be predicted in advance.

The authenticity of the film, with its roots in real experiences of people undergoing the consequences of renal illness and organ donation, was welcomed by consultants, staff and dietitians as a powerful tool for teaching, contrasting with the more commonly used 'message-giving' health awareness-raising tools. Having encountered this approach consultants acknowledged that the story-telling power of the arts has a very useful pedagogic role by engaging the empathy of the wider community.

The project aimed to explore the connections between the science and management of food and fluid intake alongside making a film reflecting patient experience. These two areas did not sit easily together; and were never fully integrated in the project. However they were present in food workshops and recipe publication and will inform future activities of the dietitian and her team alongside the films. The films are a reflection of experience and are therefore powerful in their implicit messages about diet and fluid control, exploring the subject matter; and offering implicit rather than explicit connections between the lived experience of renal failure and the science behind it.

EVALUATION METHODOLOGY

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The evaluator was involved in formative review and reflection throughout the project. Data has been gathered through a range of methods including: examination of planning documentation for Blood Makes Noise; evaluator observations; dialogue with key stakeholders; stake holder narrative accounts; planning group discussions at beginning, mid and end points; participant reflections; analysis of participant stories and key moments; feedback notes at film screenings; responses from hospital staff in DCH and Poole and Bournemouth dialysis satellite units; guest questionnaire responses; and examination of relevant contextual documentation. A Quality of Life (QOL) survey was administered as the project began across the DCH renal unit). A further QOL survey will be carried out by the dietitian at DCH dialysis unit in Spring 2014. Data is not available for this report.

PROGRAMME OVERVIEW: AIMS & OBJECTIVES

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The project objectives were to

- Engage at least 10 people, on dialysis during the 'twilight' sessions, in exploratory work over a period of 52 weeks to develop and produce 5 films.
- Involve a further 30 dialysis patients (daytime sessions) in the project through online activity and some practical workshops.
- Bring together the renal dietitian, the artist and participants to explore the connections between the science and lived experience of dialysis and managing diet and fluid.
- Involve Jyoti Fernandes (the Real Food Bus) in joint sessions when appropriate to provide knowledge and skills in connection with food sourcing and preparation.
- Encourage families and carers to get involved and, if appropriate, deliver creative sessions in participants' homes or at Five Penny Farm.
- Engage a wider audience of patients, their families and carers through the online blog and social media.
- Build an audience for the films through the online presence. Release films as a series over 5 weeks online, shared through social networks and via the websites of patient support groups including the British Kidney Patient Association.
- Show the films to all dialysis patients at DCH on the bedside TVs and to dialysis patients within the wider Dorset cluster managed by DCH – a total of 244 patients.
- Engage renal nurses, nursing assistants as well as nursing staff in training at Bournemouth University by showing films, providing a vivid and authentic connection with patient experience.
- Screen the films locally and submit for national and international screenings at film festivals and conferences through Arts & Health South West.
- Produce a thorough qualitative evaluation of planning, process and outcomes and disseminate the evaluation in both arts and health settings.
- Deliver a symposium for medical staff, artists and cultural professionals to explore the processes and outcomes behind participatory artistic interventions in hospital settings



OUTPUTS & ISSUES

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5.1. Outputs

- Snelling's residency in the renal unit at Dorset County hospital involved 5 patients in making films about their experiences of renal disease and another 14 patients took part in activities in the dialysis units either in Poole or Bournemouth.
- 35 people contributed to the blog at <http://bloodmakesnoise.wordpress.com>.
- A 60 minute film was made including personal narratives of 5 patients and exploring tensions between hospital and home life, pressures of diet/fluid restrictions, lost time, and different experiences of transplantation (to date seen by 4425 people)
- Training sessions using film and recipe book for dietitians and renal clinicians.
- Cooking sessions with Jyoti Fernandez, planned with the renal dietitian, enabled patients and families to explore how to prepare renal-friendly meals. A recipe book devised by the 5 key participants in the film combines patient stories and experiences with memories and food and includes essential dietary data analysing recipe content.
- A teaching and dissemination programme is ongoing.
- Film screening and symposium discussion attended by 65 clinical staff, artists and patients at Dorset County Hospital (March 2013)
- The film was sent to patient coordinators of 109 renal units across the UK.

5.2. Issues

5.2.1. Mixed expectations: dietary education/creative film-making

Concern was expressed early on within the team about the way in which the questions of food and diet could be drawn into a creative process without compromising the artist's responsive approach to participant involvement. The team were aware from the outset that diet and fluid intake could be a source of tension for renal patients, and this was a primary motivator for the involvement of the hospital renal unit and dietitian. The artist however wished to enter an open-ended creative dialogue and did not wish to be seen by patients as an implicit message carrier. Such tensions are not new in the realm of arts collaborations with hospitals. In raising resources for hospital arts projects the involvement of the artist is often justified by their capacity to meet instrumental priorities, and it is only as the project unfolds that staff working with artists for the first time are able to witness the wider and potentially deeper impacts of the artistic presence on other aspects of patient well-being. This tension is well articulated by the project's coordinator Alex Coulter who chose to write about this in her narrative account: *"However from early on I realised thatexpectations of the project delivering a recipe book and a chef 'master class' didn't obviously fit with the creative aspirations.*

In addition to this I realised that Peter was not himself inclined to be positive about food as a subject being a self-confessed ‘turkey twizzler’ type! So there was always some tension around that and I think, although resolved in many ways, it is evident in the end product - the film and recipe book are not very strongly connected.” However Alex Coulter goes on to point out that once the film had been made, the team realised that it gave them access to a powerful set of stories expressing the lived experience of renal failure, and dealing indirectly with issues of diet. As the dietitian pointed out – it is much more powerful for patients to hear other patient stories, than to read a leaflet, or be told by a dietitian.

5.2.3. Staff Attitudes in Hospital

Initial reluctance of managers to commit staff time to the project was quickly addressed as the project began when staff fed back to them the value of the process to patients and their confidence in the potential of the emerging film. A senior renal consultant who had no experience of participatory arts in chronic health care contexts had expressed some reservations about what might be achieved through the project. Her views changed as the work began and she and her staff reflected that the involvement of the artist with families and patients was highlighting a wide range of important issues relating to individual and family experiences of renal illness. By the end of the project she expressed unqualified support acknowledging that: *“We need something other than the nursing medical side, its so complex [chronic illness]”*. On viewing the film she recognised its potential to raise the profile of renal disease as well as illustrating the family experience; both for staff new to renal care and for newly diagnosed patients. *“I have had feedback from the nurses that it would be helpful for junior nurses to see the film, and from senior staff that it is a good way of highlighting issues around family experience. Very useful training too, very useful for new patients – to show what they will go through. It gives a realistic view of all aspects of renal failure.”*

The responses of nursing staff demonstrate the film’s success in building empathy with patient experience: *“its really powerful for everyone on the unit to see all the range of emotions”* or *“it moved me, it made me empathise with patients”*. A nurse described a highlight of the film as: *“seeing the other side of the story for renal patients”*.

The renal consultant valued the range of perspectives and experiences represented in the film: *“I particularly liked the way the film presented a range of perspectives, across class – and all equally articulate, across type of dialysis, attitudes to donation. But it did this in a very informed and responsible way. Showed things like 5am in the morning plasma exchange – what that actually means for a working woman. David’s mother was saying perhaps what everyone thinks, but can’t say. We’d all go and buy a kidney, any kidney for the person we love. It brought out what it is for ALL family members...the way one had had a transplant, the other making PD (peritoneal dialysis) a part of life.”*

The dietitian points out the value of the film in addressing social aspects of care in a non-threatening way; and both film and the food workshops demonstrated for patients that issues around phosphate control don’t have to be dull.

All staff acknowledged that Peter Snelling’s style and approach was sensitive and very engaging. His professionalism was a key factor in building confidence of staff in the project and the renal consultant went as far as suggesting *“If we had a more permanent artist we’d be happy”*.

Peter Snelling describes his changing relationship with the ward through the project: *“I had been told not to go on the ward during change over, but people had got very used to me being there and now no-one noticed or challenged my presence. David was talking and putting himself on and I realised that I was now completely accepted here, but also that I had become very used to dialysis and the world of the unit.”*

5.2.4. Patient Experience

Each film story offers remarkable patient testimony, giving insights into the reality of living busy lives when dialysing; the complex psychological and medical associations of inter-familial organ donation as well as exposing the challenges for regular kidney dialysis patients such as boredom, lack of control, low family awareness of diet, fluid restrictions and low mood.

As well as this, patients and staff identified particular benefits of working with Peter as: creating a sense of community on the ward; enabling patients to demonstrate high levels of patient autonomy; increasing patient transparency about their illness outside the hospital; and opportunities for self expression and communication about some of the more difficult dilemmas and issues surrounding renal illness and transplantation.

During the process patients described the impact of Peter Snelling's presence on the ward: *"there's more of a sense of community on the ward with Peter in the middle"*, or *"Peter's facilitating a three way conversation between you, the machine and him"*.

The process of participation opened up a space through dialogue and film making for participants to consider their circumstances, to review them and to see them in a different light – in some cases changing perceptions of their situation. A participant's partner was able to say *"I've found things out about how you feel for the first time; the film makes it human and puts it in layman's terms"*. Patients' own footage was inter-woven with Peter Snelling's filming, enabling, in one instance a patient to interview his parents about his illness, and to tell his colleagues at work about his dialysis for the first time.

"This project has marked an end point of compartmentalising my dialysis, home, school, dialysis. I realised I didn't have to do that. It just made it so much easier to talk about it – not that we have to talk about it – its just that I don't have to avoid it any more. Having said it all to Peter it was so much easier to say it to someone else, so having taken the leap, somewhat unwillingly, I admit, its worked out really well."

His partner describes her surprise at her husband's involvement: *"I was very surprised (he) did it. He doesn't usually tell anyone. Before he would say its no-one's business other than him. Then he dragged his parents into it, and now he's made a film himself. This project made us ALL think again about how it affects us"* (Sarah).

Participating patients were keen to explore the effects of renal illness on families: *"the dialysis takes you away from your children, you miss out on ordinary things like parent's evenings, holidays"*.

Feedback from renal patients who had seen the film but not been involved in making it were equally positive highlighting its value in building a sense of community amongst kidney patients as well as informing the general public, or those new to kidney failure: *"As a kidney transplant patient who has undergone dialysis and plasma exchanges this video was brilliant to watch. Well done to Peter for creating a wonderful film. This will help so many patients who are new to the world of kidney failure and also makes me feel less alone with the disease"*. (online response)

The film's emphasis on renal patients as people living full lives addresses the tendency for them to be seen by both hospital and the outside world as 'patient' first, and professional, wife, mother, father second. Patients were hopeful that other renal patients would see the film and be encouraged to take ownership of their circumstances. They are also hopeful that the film will raise public awareness of the need for organ donors.





5.2.6. Engagement of wider publics and medical staff

Renal illness is not aired in the public realm as much as other chronic illnesses such as cancer and heart disease, so there was a strong incentive to address public ignorance about renal failure. As the partner of one participant said: *“people think kidney failure is to do with drink or drugs, not because of a virus, for example”*. (Brian, Partner). One patient told of her return after a transplant and the surprise of her neighbours that she was not longer going to dialysis.

The project worked with a group of highly motivated and articulate patients and families, who demonstrate very positive ways of living with renal illness. It was hoped that representing their experiences would inspire the many renal patients who tend to be less active. It was the team's good fortune that the five protagonists in the film also represented several significantly different aspects of renal illness and a range of attitudes to donation and dialysis. Between them their stories include: regular haemo-dialysis three-times weekly in hospital; peritoneal dialysis – conducted at home; inter-familial transplantation; and altruistic live kidney donation (non-familial).

The film was praised by professionals particularly for this range and its approach to the cyclical nature of renal illness. *“It revealed the complexity of transplants and the life-long cycle of dialysis: Transplant; Dialysis; Transplant; Dialysis. The film reflected the cycle of the life of the organ.”* (Renal Consultant). Indeed this has already widened its distribution to pre-transplant as well as pre-dialysis patients. A particularly moving aspect of the work is its presentation of the very difficult feelings that can surround inter-familial donation.

Responses from professionals from other hospitals acknowledged that it helped them to consider patient experience in a new light.

“It included perspectives I had not really considered before (e.g. views around transplant). It reinforced the impact that kidney disease has on peoples' lives. People react differently to their condition and their treatment, and have different views about it. It affects peoples families and social circles as well. It was a privilege to have a brief insight into peoples lives, and how they feel about their condition and treatment.”

“It made me think about the demands that services put on people affected by kidney disease, which I hadn't really thought about as clearly as I did whilst I was watching the film.” (Quality Improvement Lead, Cheshire and Merseyside Strategic Clinical Networks)

“This is a really memorable project which could have far-reaching impact on healthcare providers, patients and families, and potential donors.” (NHS Manager)

“It gave a real sense of what all the patients and their relatives were feeling and the effects it was having on their lives”. (Living Kidney Donor Liaison Nurse)

"As an ex PD nurse I found the film very informative both emotionally and practically". (Nurse)
A link to the film was sent directly to the patient coordinators of all 109 renal units in the UK. One hospital has added the film to their patient information kiosk, and another response endorsed the value of hearing from patients directly: *"Thank you for the link. Loved the film. Lots of honesty and very few health professionals! Will make it available to the pre RRT patients."*

The positive views expressed by medical professionals echo Stilgoe & Farook (2008) who point in their research to the benefits for the medical profession working alongside artists or other professionals who use softer skills alongside clinical expertise in developing effective communication with patients: As Jan Cohen-Cruz reflects: *'For public, inclusive art to benefit our shared civic life, we need opportunities that create intersections between engaged artists and people from other disciplines and communities working towards the same goals'* (Cohen-Cruz 210: 196 – 197)

5.2.7. Is this Art?

From the outset the question of whether the film-making was 'art' was present. A reviewer of the original Wellcome Trust application expressed concern that the project lacked artistic ambition and might result in the use of an art form to inform, rather than explore issues. At the final screening the debate re-emerged with an audience member asking: *"is this art"*? These comments go to the heart of the complexity of definitions of practice in the field of participatory arts practice in bio-medical settings (Raw. A. 2012). Peter Snelling himself initially resisted the label of 'artist'. But he records that the project has marked an important shift for him as he has for the first time begun to define himself as an artist rather than a film-maker. In this new departure he describes his approach *'exploring in an open ended way and recording that process'* as arts making; implicitly acknowledging the centrality of *'not knowing'* and *'intuition'* in his approach; his reliance on gaining participant commitment through sharing personal stories; and his recognition that the relational aspects of his *'arts-making'* are inextricably wound up with its content. He writes: *"I have really seen that being alone with the contributors gains you a much more intimate relationship that reaches beyond the film and into just knowing and liking each other. It is key to me that the project is about this relationship"*. There is an implicit reference here to the importance of brokering mutuality 'liking each other' in his relationship to participants. These features correspond with current ethnographic research by Anni Raw (Centre for Medical Humanities, Durham) which seeks to identify characteristics of the participatory creative practices in health settings.

5.2.8. Exploring connections between the science and lived experience of dialysis (managing diet and fluid).

The involvement of families in cooking activities was intended to assist renal patients in communicating about their needs, as research has shown that families and partners of renal patients are often not aware of dietary needs, thus compromising the fluid and diet intake of patients. Patients were invited to design their own renal friendly recipes which were then tested at home and in cooking evenings with the food producer, and resulted in the production of a book of renal friendly recipes. This included key information about potassium, salt and phosphate levels in foods, and has provided another useful resource for dietitians in raising awareness about diet. The recipe booklet has been widely distributed in the Dorchester, Bournemouth and Poole units, and future work, outside the scope of this project, is planned to continue the cooking activities and the important messages about diet and fluid intake to renal patients in other hospitals in the county.

TRAINING, EDUCATION & DISSEMINATION

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The film and booklet are being used for training purposes at DCH and Poole and Bournemouth satellite units. Staff have identified the value of the films in preparing pre-dialysis and first time kidney failure patients for dialysis or other clinical interventions. Screenings of the film and discussions have already taken place at:

- DCH dietetic department staff meeting.
- Book and film sent to Bournemouth University Student nurse programme
- Screening at the Richard Bright Renal Unit, North Bristol NHS Trust.
- Renuka Coghlan teaching sessions at Poole and Bournemouth renal units.

The serious illness of DCH dietitian, delayed dissemination plans which are now in place:

- Recipe books and film to be made available through dietetic clinics to all nephrology/renal patients or patients with dietary restrictions
- Film screening at county wide study day for Dorset Dietitians

Additional funding is being sought via Arts in Hospitals and British Kidney Patient Association for further collaboration between the dietitian and food producer to develop a food trolley project, offering renal friendly snacks as an alternative to the crisp and chocolate trolley run by the League of Friends, initially at Dorset County Hospital, and transferable to Poole and Bournemouth. It is significant that the relationship with an external food professional has emboldened the dietitian to put her own food trolley project into action. The complex negotiations with League of Friends, ward staff and hospital catering which will enable this to happen, had discouraged her in the past from initiating this important strategy to improve patient dietary habits whilst on dialysis. Peter Snelling is very motivated to further disseminate the film and he has applied through the Big Lottery to fund an ongoing programme of film viewings and workshops in renal units around the UK.

The DCH Arts Coordinator is also raising further funds via the BKPA and Dorset Kidney Fund for further local dissemination in Dorset hospitals.

DATA

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Patients directly involved in making the films at Dorset County Hospital	5
Family members directly involved	10
Patients at Dorset County Hospital involved in food activities	8
Nursing/care staff at Dorset County Hospital	8
Film screenings and workshops at Bournemouth and Christchurch Hospital	30
Film screenings and workshop at Poole NHS Trust	5
Blog contributions	27
Audiences for Film	
Web hits on Vimeo via My Pockets uploads (selection by VIMEO for the channel - socially minded documentaries)	3,348
Attendance at Film Screening, DCH	60
British Renal Society Network via attendance at British Renal Society National Conference and Poster presentation	700
NHS England: Cheshire and Merseyside Strategic Clinical Networks	200
Bristol Culture, Health & Wellbeing conference June 29 2013 screening/discussion	15
Link sent to patient coordinators in 109 renal units	109
National Clinical Director (renal) R.Fluck – NHS and BRS President (Tweeted film to his followers)	unknown
British Kidney Patient Association (web-link to membership http://www.britishkidney-pa.co.uk)	unknown
TOTAL (known)	4,525

Press & Media

21st June	Wessex FM radio and on their website http://www.wessexfm.com/news/dorsetnews/1002677/kidney-patients-helped-by-dorset-arts-project/
21st June	Radio Solent
3rd July	View From Dorchester weekly paper http://www.viewfromonline.co.uk
18 June 2013	Dorset Echo

Websites

www.dchft.nhs.uk/about/arts.html
www.facebook.com/ArtsInHospital
www.britishkidney-pa.co.uk
British Kidney Patient Association - web piece:
www.britishkidney-pa.co.uk/news/67-five-views-of-life-on-the-transplant-list-caught-on-film



Expenditure

Artists fees	12,570
Dissemination and marketing	7,180
Film production costs	4,500
Evaluation and administration	5,150
Food advice and development	3,720
Travel, equipment and other expenses	3,380
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TOTAL	36,500

Income

The Wellcome Trust	25,500
British Kidney Patient Association	11,000
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TOTAL	36,500

PROJECT ACTIVITY

Timeline

Jan-February 2012

Funding decisions confirmed and more detailed planning undertaken

Discussion with dialysis patients. Informed consent for participation taken.

Meeting between artist and renal staff to introduce ideas and methods of working and to discuss food consultant role.

Evaluation base line interviews conducted and wider staff community informed about details of project.

March-September 2012

Artist is 'in residence' once a week during the 'twilight' sessions (6 – 11pm).

The renal dietitian present for at least two sessions a month. Food consultant to join collaborative sessions as and when appropriate.

Engaging carers and relatives where appropriate and planning for any sessions off site.

Evaluation input from participants, staff and artist.

Creation of online blog and use of social media to allow participants and other patients to contribute.

June-August 2012

Review meeting

Focus on blog with wider group of participants.

Cooking workshop 1: recipes drawn up.

Additional sessions during day-time hours both with an extended group of patients and with carers and relatives.

Twilight filming sessions continue.

September - November 2012

Filming complete.

Editing begins with regular consultation with patient contributors.

Cooking workshop 2 and celebratory meal for participants and their families, artists, scientists etc.

December 2012 - March 2013

Consultation with patients as films are edited.

Dissemination event and discussion at Dorset County Hospital with invited local and national audiences.

March-June 2013

Distribution of DVDs dissemination via British Renal Society Conference, Manchester; Arts, Culture and Wellbeing conference, Bristol.

Developing further links to patient groups in Dorset staff training opportunities developed at Poole/ Bournemouth and Dorchester

September - November 2013

Final reporting to funders

CONCLUSIONS

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The key aims and objectives of the project were largely met. Particular strengths were the strong relationships between hospital and artist; the quality of patient engagement with artist; increased sense of community on the renal ward; positive responses and feedback to the film from general public and clinicians; the realisation of plans to use the film as a teaching resource; the involvement of a food producer with renal patients and their families; the production of renal friendly recipe book for wider use and some evidence of improved dietary management resulting in better phosphate results within the target group. The use of blog and online engagement with renal units was less successful and worked best when provoked by direct contact with artist or nurses. The project raised a number of issues which may be of interest to the wider community of artists working in health settings.

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The films are both a moving testimony to the 5 patients who were involved, and also a useful resource for hospital educators and others who are using them to involve the general public and new renal patients with issues surrounding diet and lifestyle, as well as social, psychological and ethical issues surrounding organ donation.

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The project aimed to explore the connections between the science and management of food and fluid intake alongside making a film reflecting patient experience. These two areas did not sit easily together, and were never fully integrated in the project. However they were present in food workshops and recipe publication and will inform future activities of the dietitian and her team alongside the films. The films are a reflection of experience and are therefore powerful in their implicit messages about diet and fluid control, exploring the subject matter, and offering implicit rather than explicit connections between the lived experience of renal failure and the science behind it.

CREDITS



Medical staff

Dorset County Hospital:

Jo Taylor, Renuka Coghlan and the team on the renal unit.

Richard Bright Renal Unit, Southmead Hospital, Bristol:

Najib Cahdi (Surgeon), Tracey Fleming (Transplant coordinator)

Plasma Exchange Team

Film maker/artist: Peter Snelling

Food consultant: Jyoti Fernandez

Musician: James Price

Editor: Jesse Lawrence

Arts in Health Coordinator: Alex Coulter – to April 2013

Alex Murdin – from April 2013

Evaluator: Anna Ledgard

Bournemouth satellite dialysis unit: Gloria Wiley

Poole dialysis unit: Karen Kettle

REFERENCES



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Healthy Conversations: The talking cure. Demos.

Cohen-Cruz, J. (ed) (1998)

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Engaging Performance: Theatre as Call and Response.

(London: Routledge).

Raw, A. (2013)

Ethnographic evidence of an emerging transnational arts/health practice: perspectives from UK and Mexican participatory Arts Workshops - presentation at Bristol Culture, Health & Wellbeing Conference June 2013

Patients and families involved in the film project
at Dorset County Hospital.

Lauren

Beck

Nigel

Ollie

David

Sarah

David's Mum & Dad

Jodie

Denise

Brian

Ben Margaret

Kevin

Trisha and sons

Bob

Julia

The Beavers

Other Patients at Dorset County Hospital:
Jenny, Chris, Alan, Mary, Richard, Muriel, Joan

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www.mypockets.co.uk/bloodmakesnoise.htm



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