

# **BEDSIDE MANNERS**

## **Evaluation**

Conceived by artist Sofie Layton  
and created with parents of children  
attending Evelina London Children's  
Hospital. Produced by Anna  
Ledgard.

**February 2014**



Photography by Stephen King

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# 1 INTRODUCTION

Bedside Manners was conceived by artist Sofie Layton and produced by Anna Ledgard. It was created over 9 months with parents of children attending Evelina London Children's Hospital. From November 2012 – July 2013 Sofie Layton spent 1.5 days a week in the hospital Dialysis Unit, Paediatric Intensive Care Unit (PICU), hospital school and main wards working with parents and families alongside Evelina Hospital School teaching staff, nurses and play therapists.

Parents of ill children spend a great deal of time in hospital supporting their children. Understandably, medical care and education provision is focused on the child with parents spending much time as observers and carers. This project sought to find an alternative way to involve parents through a series of creative processes, giving voice to their knowledge and feelings, and providing a resource for other families attending the hospital. Initially parents were invited to create postcard-sized art works using different techniques, such as embossing the form of a heart, kidney or cellular/bacterial form which has been screen printed onto thin aluminium rectangles, or embroidering organs which related to their children's illnesses. During the process Sofie collected and recorded conversations about their experiences and sounds from the hospital and these were made into a sound-scape by composer Jules Maxwell.

The images and soundscape were then incorporated into an installation located in the Evelina Hospital Atrium and open to the general public for a week in July 2013. For families, throughout the time a child is in hospital, the hospital bed space becomes their world. This

final installation re-imagined that bed space and imbued it with the bravery, resilience and fragility which was expressed by the parents as well as the commitment and dedication of the hospital staff.







## 2 SUMMARY

Bedside Manners was a successful project which met its main objectives and exceeded expectations in a number of areas. The project was planned and carried out in collaboration with hospital ward staff and hospital school. A collaborative arts process was introduced in the hospital over 9 months and a total of 36 parents and children participated. Professional development was held for 30 staff. Evidence from parents and staff confirm that engagement in the arts had offered parents a channel to express their feelings and to contribute to a powerful collective artwork, known to have been seen to date by over 200 people. The project has resulted in further requests for the project team to work in the hospital in arts collaborations which can meet hospital objectives.

### Features which contributed to the success of the project were:

- the project team's strong relationships with the hospital established through earlier projects;
- ongoing dialogue and reflective relationships between team and staff;
- an artist with a highly skilled artistic practice and understanding of the workings of the hospital;
- a schedule devised responsive to needs in the hospital;
- interdisciplinary art forms which allowed many entry points and rewarded success.

*"Makes you reflective of parents' and children's lives and thankful for yours...."*

**Nurse**

*"Amazing to hear the perspectives of our families. We wonder if we could ever be that strong"*

**PICU Nurse**

*"Thank you for this very moving, reflective piece, which reminded me of why I do my job"*

**Psychotherapist**

## Specific benefits of the arts were:

- their capacity to provide an abstract space to explore feelings;
- embroidery and embossing techniques providing a 'haptic' process to engage touch and feeling;
- the capacity of the arts to engage audience and staff empathy with the parent and patient experience.

"This is a piece which should be used as part of nurses', doctors' training"

**Teacher**

"A touching insight into peoples' hardship"

**Arts Professional**

## Challenges

Communication across the hospital departments was at times difficult, tending to rely on artists communicating with individuals within departments, because of the lack of existing inter-departmental communication channels.





### **3 EVALUATION METHODOLOGY**

The evaluation explored the impact of the project in terms of engagement and participation of staff and parents; and its effectiveness as a model of good practice for arts collaboration with a hospital.

The project was self-evaluating with the producer/educationalist as participant evaluator embedded within the project. A qualitative, mixed methods approach was adopted. This involved observations of arts sessions (including individual, group and family sessions and training); analysis of generated arts content; in depth interviews with key participants and professionals; a post project group discussion; and responses of public/staff to installation. Quantitative data was gathered against outputs (participant numbers, sessions attended etc.). Interview and focus group data was recorded, transcribed and analysed identifying common and divergent themes and unforeseen outcomes against project objectives. Although it had been hoped that the hospital might be administering its own well-being questionnaire offering us the potential to gather data, this, in the event, is not available at the time of writing.







## 4 PROGRAMME PROGRESS AGAINST ORIGINAL OBJECTIVES

### 4.1. To provide a collaborative arts making process

Artist Sofie Layton introduced a collaborative arts making process integrating drawing, print making, textiles, sculpture, and story telling.

### 4.2. Providing Professional Development

Alongside the residency Sofie Layton ran 3 training sessions for play therapists, nursing and teaching staff. These were attended by a total of 31 staff.

### 4.3. Complementing hospital patient and parent experience initiative “Safe in our Hands”

Hospital Patient experience representatives attended the installation, however The Safe in Our Hands initiative was wound up during our project (see 5.2.)

### 4.4. Empowering and consulting parents/peer forum/trialling different methods/focus on parents/counteracting ‘dead’ time or boredom for parents

Sofie Layton trialled different methods of engagement, and different times for sessions, in order to be available at times which did not create conflict for parents. Parents enjoyed working together and the peer support provided by the project and the resulting installation provides a moving testament to their experiences. Feedback from staff and patients was unanimous in its praise of the project.

*“This project has so much meaning for me as a mummy of a 9 year old boy who has been here at the Evelina for the past 8 months. Meeting Sofie and finding tiny moments to escape in to focusing on something other than all the daily experiences and emotions we have had to deal with on Thomas’s very difficult and often traumatic journey while here, has been very helpful for me. Seeing all the works together is wonderful and I think the audio element really captures so much of what we, as parents, unite in feeling. And today we are taking Tommy home – HOORAY!”*

#### 4.5. To consult parents about the process of absorbing new medical information and making informed choices.

Conversations did incorporate discussion of medical information and this was included in the final installation. It also gave parents a peer forum to discuss their experiences.

*"It might just be classed as sewing to some, but to me, as a single mum, it feels like a holiday."*

#### 4.6. Complementing hospital policy

The project was welcomed by hospital senior management as a means of meeting hospital aims to improve parent and family experience. Sofie Layton and Anna Ledgard attended the Evelina London Hospital's management Forum twice (attended by all heads of departments and clinical lead staff) and reported on Bedside Manners (dates: February/June 2013) within the hospital's patient experience strategy.

#### 4.7. Transferable Model of collaboration

The project has demonstrated the potential of well-planned arts interventions, designed with staff, and developed in partnership over time, to fulfil important hospital priorities, in this case enhancing parental and family experience of the hospital. Relationships with clinical, nursing and school staff were strong; senior management supports the idea of future developments; and the track record of the team is well respected. "Your projects are always of the highest professional calibre...we hope you will bring many other projects to our children's hospital in future" (Hospital School Head teacher).

#### 4.8. Developing artist's own practice

In preparing for this project, Sofie devised techniques and strategies in response to parental involvement, realising that she needed to introduce a range of possible entry points for parents. The final installation involved new techniques of printing and embossing and an innovative and unique re-visioning of the bedside rooted in the conversations and workshops with parents.

#### 4.9. Create permanent installation/art work

The final installation took the form of a re-imagined bedside cubicle with voile curtains printed with parents' words and work; a purpose built screen incorporating embroidered and embossed organs interspersed with medical iconography and objects; and a sound-scape of parental and staff voices. A high quality exhibition standard 2-dimensional visual screen has been adapted from the installation and is permanently exhibited in the Evelina Atrium and it is planned that the full installation will be exhibited by GSTT charity in September 2014.







## 5 THEMES EMERGING

### 5.1. Personal Testimony in evaluation

The Bedside Manners evaluation was conducted as an enquiry involving participants, artist and hospital staff in regular critical reflection. This evaluation recognises the personal narrative as an important source of evidence of intrinsic benefits such as the channelling of difficult emotions and improvements in parental well-being. On-going reflective conversations with those closest to making and experiencing the work itself, are the backbone of an ethical and responsive collaborative arts approach. Matarasso's recently published discussion of quality in participatory arts offers a useful perspective on this "the quality of self-awareness and critical reflection exercised by artists working [in] participatory contexts, and the extent to which that reflection is open to all participants, is central both to an ethically-defensible process and to the probability of programmes achieving their stated goals." (Matarasso, F. 2013 p.1).

### 5.2. Partnership with the hospital

Partnerships between artist, school and hospital were characterised by careful negotiation and dialogue. The involvement of the hospital and the school in an earlier project For the Best (2009)<sup>1</sup> left a legacy amongst senior staff in

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<sup>1</sup> For the Best (2008 – 2010) conceived by artist Mark Storor and produced by Anna Ledgard explored the experience of living with renal illness in collaboration with Evelina London Children's Hospital and Evelina Hospital School, Artsadmin, the Unicorn Theatre London, Royal Liverpool University Hospital, Unity Theatre Liverpool and young people, families, artists and schools in London and Liverpool. Funded by the Wellcome Trust, Arts Council England, Liverpool City Council & the Hedley Foundation.

school and hospital of respect and understanding for the role that art can play. A project steering group involving artist, producer, teacher and PICU nurse lead or play therapist met regularly to review progress. This meant that the hospital was actively engaged in defining the terms of engagement, choosing that the artists attended on average 1.5 days per week over 9 months, and making the decision to work with parents alongside the Safe in Our Hands initiative, the hospital's strategy to support the family experience of hospital. Hopes that involvement in such an initiative would assist the practice of working across departments were compromised when the Safe in Our Hands initiative foundered during the project, evidencing the considerable difficulty, even for hospital staff, of implementing social welfare strategies involving multiple hospital departments. The difficulty of working in partnership across departments in hospitals was acknowledged by all partners without exception (play therapy/education provision/intensive care nurses/consultants) citing as reasons: the lack of structures for communication between areas of care and the lack of a 'joined-up' approach to patient care.

Despite this Bedside Manners ran smoothly, relying heavily on two individuals, Jane Sivyer (play therapist) and Russell Ventham (teacher). They were well known and trusted by both colleagues and parents and initially did all liaison on the wards with parents and nurses. As the project progressed, Sofie Layton became known and her methods trusted, and she was able to make direct contact with families.

### 5.3. Methods of Involving Parents

The project evidenced a sharp shift in enthusiasm and engagement from beginning to end. Initially when approached by play therapists, parents were reluctant to be involved: "parents weren't aware of what they



were participating in, so they didn't know what they were saying yes or no to" (play therapist). They were also understandably reluctant to leave the bedsides of their very sick children. The artist's response to this was to make herself available in the main Atrium for parents to 'drop in' and experience her process as it suited them. She knew also that she would be visible through the glass windows of the wards, enabling parents to look at what she was doing. This strategy worked and by the end of the first month parents were attending regularly and described the experience in unequivocally positive terms: "I think this should be a permanent feature.....it's a life-line" (parent). Another parent described how her time was often spent in hospital "I had nothing to do.....worry, fret, worry, fret". The project had provided a positive activity countering negative feelings, building self-esteem and developing a sense of community with other parents, as well as a confidence and pride in their artistic contributions. By the end of the third month nursing staff were 'referring' parents to the project from the wards.

#### **5.4. Benefits of involvement in a creative process**

The project provides evidence of short-term improvements in wellbeing amongst parents and children particularly during the process of making the work. Whilst the final public outcome is an important indicator of the quality of the artistic process, the extended opportunity for participants to be creators of the work through a deep participatory process was considered more valuable by the hospital staff working most closely alongside us. This is articulated by teacher Russell Ventham: "It has been a privilege to be part of this project and to see how the 'making' has been a welcome channel for parents to join together and share their experiences, whilst, secondary to this, producing exquisite art pieces".

## Specific Benefits

### 5.4.1. Different quality of time

References to the arts process providing “a different quality of time” were made by a number of participants. A parent’s time in hospital is not theirs: friendships, work and family life are put on hold. Several described how Bedside Manners had given them time for themselves: “This is my time” reflected one mother. Others described how the art activity afforded them a temporary escape from their difficult reality: “being in hospital makes me feel like my mind is cracked.....this helps me forget.....”. Another mother described the arts making as ‘time to do something normal’. Others pointed to heightened levels of absorption offered by the artistic process: “you forget where you are when you are engrossed” or “you have to pay the stitch your full attention....the conversations and the sewing, they slow down time.” Another mother who read the Koran whenever she was not with her daughter described how: “Before I don’t like hospital...I read Koran before. When I woke up I thought I was in hospital. So now I.....make sewing and I like being in hospital more”.

### 5.4.2. Identity of participant as ‘artist’

Parents in hospitals tend to have a reduced identity, they are perceived primarily as the parents of a sick child, and their professional and wider identities are not known. Being permitted to be ‘artist’ in this space was empowering. This idea has been explored by C. Kegan: “the development of identity as ‘artist’ – often in the context of there being few identity spaces available for people - become important benefits”. (Kegan. C. quoted in White, 2011.)

#### 5.4.3. Arts as another dimension/"heart-teaching"

Artist Sofie Layton explains the quality of 'other space' that can be provided by the arts process through which parents can contribute personal and significant meaning, without necessarily vocalising it. A play therapist talked about the art bringing "specks of emotion, of humanity, in this big medical machine world". When she was asked what value the artist brought to an acute medical environment, she made a comparison with the visits of the clown to the wards: "it's huge, compared to a clown, the artist brings so many more dimensions ..... They are allowed to explore feelings, art can explore feelings, and what it feels like, and then express them, but not directly, but through the art". The father, for example, who embroidered a kidney the same size as his son's tiny kidney, reduced through illness, and used the colours of his son's favourite power ranger to leave his personal mark. Or the mother, encapsulating the capacity of the work to engage emotions, describing the work as "heart-teaching".

#### 5.4.4. Arts providing a Haptic space

Sofie Layton suggests that her deliberate choice of starting with an organ's outline and then embossing into it, avoids the scariness of a blank sheet of paper, and connects to the touch of the maker. It provides a tactile three-dimensional sculptural process and enables parents who feel that they have no art skills to succeed. In exploring the meeting point between artist and participant in the work of Mark Storor, Sue Mayo describes the process of the artist as 'taking advice' from the work as it is in progress, in order to build a collective work of art. Here too the making and embroidery are the meeting point between artist and parent, and also between parent and parent – a



shared place of connection through touch (Mayo, 2014, 222).

#### 5.4.5. The artist's process and issues of artistic ownership

Sofie Layton's high quality artistic practice was commented on by staff, parents and children. They also spoke of her lovely manner with parents, her adaptability and her flexibility. It was noted that she did not disrupt the time of other professionals, understanding she had to create ways of working that may be changed at any moment due to the unpredictability of the day to day life of an acute children's ward.

Mayo (2014 p. 221) explores the sense of unease that can exist about ownership of the creative process in participatory work. She suggests that: "The artist 'proposes a setting', a structure within which the freedom to play can exist", and continues, "it is helpful to consider these clear images of the artist as a person with particular skills, engaged alongside a person or people with particular skills, and discovering, in the joint work, the creative possibilities, both 'what is already there and what might occur'". The artist in this instance is "both following and leading" (Mayo 2014 p. 224). This is very true of Sofie Layton's process. Sofie provided materials and the frame: the deliberately chosen intimate scale of the embroidery squares, the particular range of colours, the additional objects for parents to choose from. Parents in turn chose from these materials and imbued meaning into them. The arts-making at this point is a co-producing, reciprocal exchange. However whenever participatory projects have a public outcome, there is likely to be a moment when the artist needs to step back from her deep immersion with participants in order to translate the material into a public form – this is the

moment when Mayo's "sense of unease" can occur. Such unease did not occur with Bedside Manners and I suggest that this was due to reciprocity of the relationship built between Sofie and the parents. So that when she did withdraw to incorporate all the work into the final piece, parents trusted that she would include and honour their work in the final piece, as she had in the process of making it.

#### **5.4.6. Benefits to children**

A specific objective identified by teaching and nursing staff was to encourage parents to take time away from their children and to undertake an activity which offered them some respite from their situation as carer/parent. This strategy had the added benefit of relieving pressure on their children, most of whom were acutely aware of their parents' anxiety. As play therapist Jane Sivyer said: "The child can sense if the person caring for them is relaxed and not stressed out". A number of the children expressed pleasure that their parents were doing something that they enjoyed. Teacher Russell Ventham described the opening night of the installation as like a reversal of a parents evening, with the children proudly seeing their parents' achievements, a reversal also of the tendency for the focus of both medical and educational achievement to be on the child.

#### **5.4.7. The Importance of Beauty**

Many people commented on the beauty of the work, both whilst it was being made, and in the final installation. A mid-project slide presentation to the hospital management (Evelina Forum) resulted in a spontaneous round of applause, and many comments about the delicacy and beauty of the art works. The word 'beauty' recurred in the visitor comments

book: “this is the most beautiful embroidery in the world” or “you have opened this magical space to feel these stories and lives with such love, such beauty, such care”. Sofie Layton described how parents spent long hours on their work: “it was almost like the emotional need to create something beautiful and tangible in that awful, awful space is really important”. This connection between visual beauty and the emotions was also perceived by the viewer one of whom said: “you could see the woman's feelings in it”.

#### 5.4.8. Audience Benefits

Audiences for the installation came largely from within the medical profession: hospital staff, nurses, consultants, play therapists, parents, families and visitors to the school. Their comments demonstrate the effectiveness of the art in engaging empathy.

In their work on the professional development of nurses, Galvin and Todres (2009) discuss the importance of maintaining the quality of ‘open-heartedness’ and suggests that this comes from experiencing the ‘felt sense’: “The felt sense is the way we bodily experience meanings that are implicit in our relationship to situations, people, and things. It is a way in which our more abstract ways of knowing are implicitly connected to more personal and unique experiences that make them meaningful (Gendlin 1981)”. The staff comments point to the success of Bedside Manners in accessing this relational connection between staff and parents. This is a powerful argument for the arts in hospitals and has particular relevance when the institutional and structural contexts of nursing today can work against experiencing such opportunities.

*“Makes you reflective of parents' and children's lives and thankful for yours....”*

**Nurse**

*“Amazing to hear the perspectives of our families. We wonder if we could ever be that strong”*

**PICU Nurse**

*“Thank you for this very moving, reflective piece, which reminded me of why I do my job”*

**Psychotherapist**

*“This is a piece which should be used as part of nurses', doctors' training”*

**Teacher**

*“A touching insight into peoples' hardship”*

**Arts Professional**

*“A beautiful and touching experience celebrating strength in the face of human frailty”*

**Nurse**

*“Thank you for making it possible to glimpse other peoples' lives and see beauty in embroidered threads and deep attention to each moment”*

**Arts Professional**

## 5.5. Sustainability

An ambitious aim for Bedside Manners was that it should act as a model for building and sustaining partnerships within the hospital and developing and promoting the role of the arts in future. The GSTT charity specifically asked that the project team consider sustaining the legacy of the project without further external funding.

Hospital and school staff recognise the integrity of the approach of the Bedside Manners team: "Your projects are .... founded on strongly held beliefs and executed with deep-seated integrity..." (Hospital School Head teacher). Specific legacies include the development of skills for staff and play therapists; deeper understanding for school staff and play therapists of partnership working; staff recognising the benefits and making a value based distinction between long-term collaborative partnerships with artists and one-off artistic interventions. The project presented its findings at Evelina Management Forum meetings, so senior management within the hospital were informed about the project and senior managers attended the final installation. There is some evidence in their comments of a shift in understanding about the capacity of art to engage the emotions at a profound level: "[Bedside Manners works] on so many levels and will undoubtedly make waves affecting and supporting others, whether parents, medical staff, nurses or visitors". A further legacy is that strong partnerships and a relationship of trust with this team are now well established both within the hospital and the school. Both hospital and school have asked that we return with ideas to develop future projects within the hospital in partnership with hospital clinicians and departments. For example, a specific request for further involvement from the Bedside Manners team has come from the Neo-natal Intensive Care Unit at Guy's and St Thomas's Hospital. However initial discussions suggest that funding for such projects would need to be raised

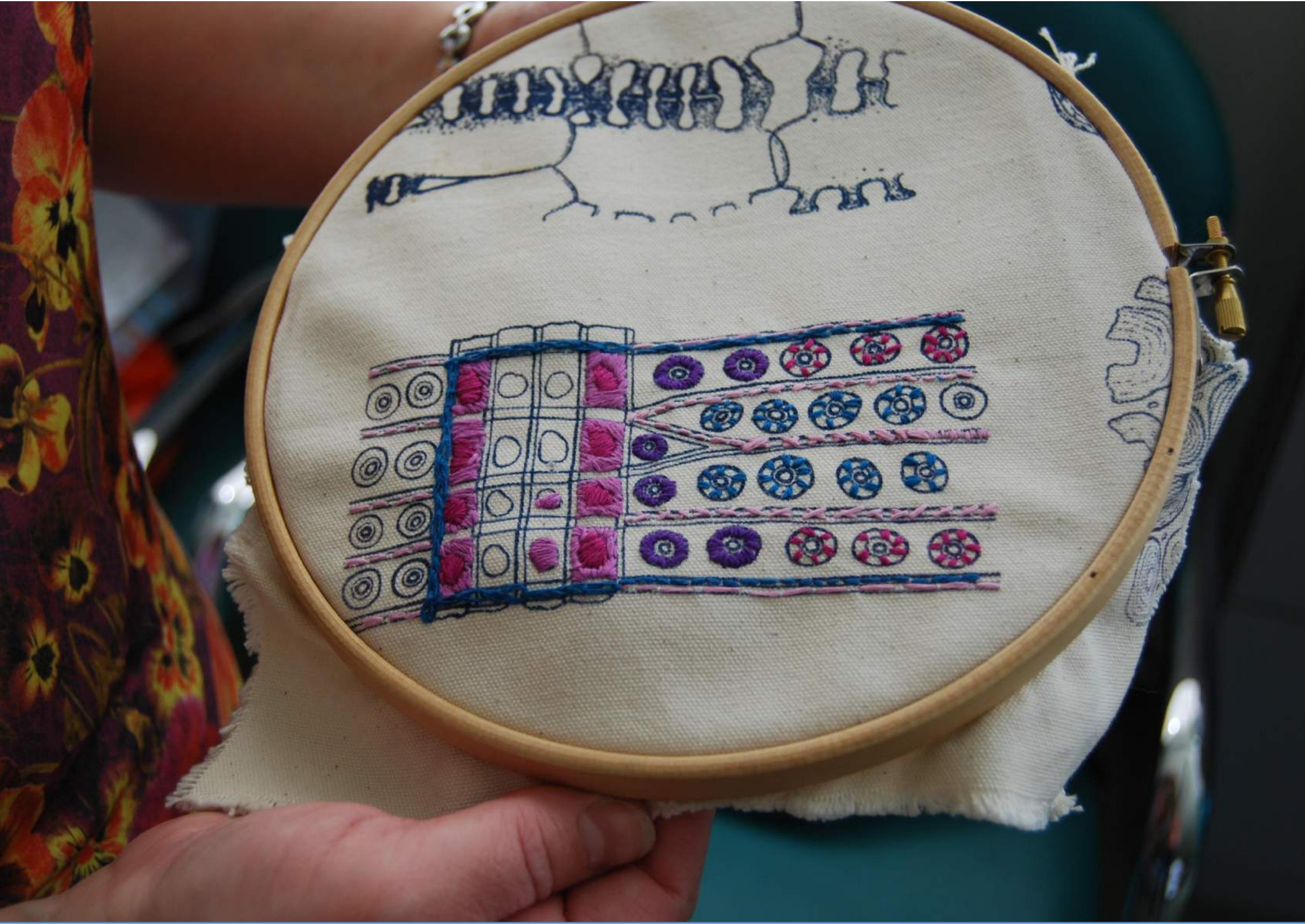


externally. Whilst hospital and school can provide staff time, spaces and liaison, they cannot provide funds at present from core budgets. The team is also in dialogue about a future development of the model of Bedside Manners with Southampton Children's Hospital renal unit and transplant clinics (which provides transplant follow up for children who have had transplants at Evelina).

The physical legacy of the project was the Bedside Manners installation which was visited by over 90 people during the 4 days it was open. There were calls for the installation to be open for longer, however this was not feasible due to the sensitivity of the soundscape and delicacy of the exhibit, they could not be left without supervision. The screen and descriptive panel continue to be exhibited, but the installation and soundscape are in storage. The installation was invited to Westminster Arts Programme the Arts of Wellbeing 4 day conference in November 2012, but in the end the conference could not provide the necessary supervision or appropriate space to exhibit the installation safely, so this did not take place. Guy's and St Thomas's charity plans to exhibit the screen, installation and soundscape at its children's health exhibition in Autumn 2014 at the Guy's and St Thomas' charity Francis House site.







## 6 DATA

Patients directly involved in making Bedside Manners	26 (known names) 10 <b>Total 36</b>
Nursing/Care Staff	8
School Staff	8
Artists	8
Attendance at discussion/opening	25
Audiences at Installation	90
Bristol Culture, Health & Wellbeing conference June 29 2013	15
British Kidney Patient Association/Guy's and St Thomas's newsletter/artist websites	Hits Unknown
<b>TOTAL</b>	<b>190</b>



## 7 FINANCIAL REPORT

### Expenditure

FEES	26850
PRODUCTION/RESIDENCY COSTS	9300
TRANSPORT	1650
DISSEMINATION/EVENTS	700
ADMINISTRATION/MANAGEMENT	2000
<b>TOTAL</b>	<b>40,500</b>

### Income

GUY'S AND ST THOMAS'S CHARITY	33500
BRITISH KIDNEY PATIENTS ASSOCIATION	7000
<b>TOTAL</b>	<b>40,500</b>



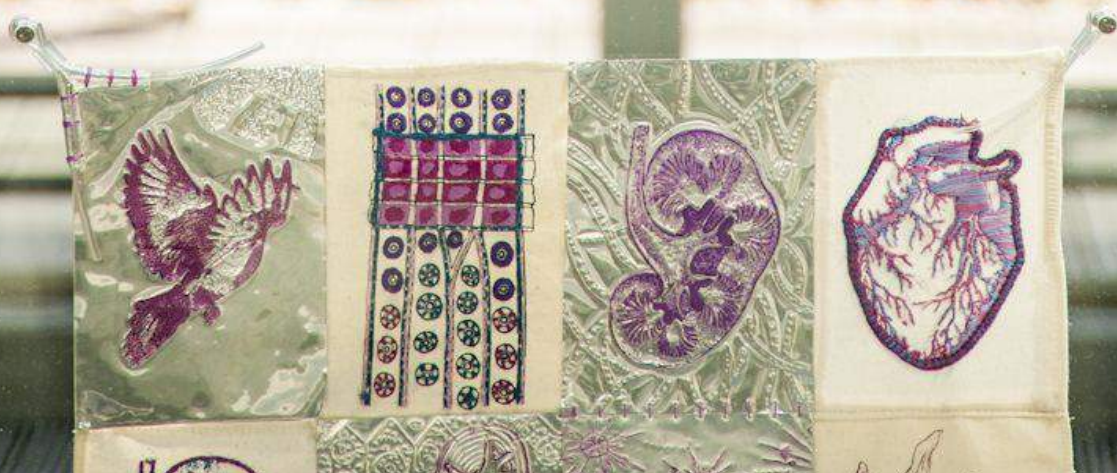
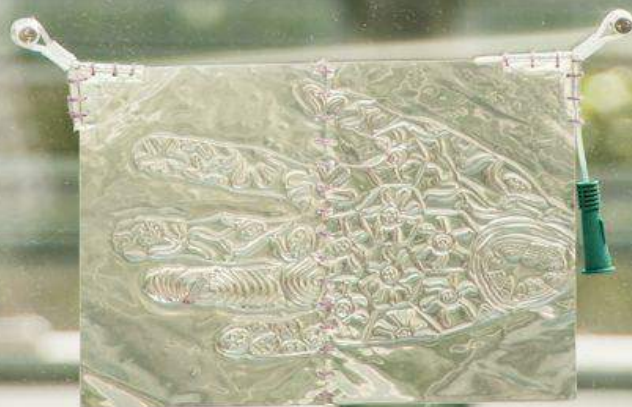


## 8 PROJECT ACTIVITY TIMELINE

### Project Milestones

- September 2012 - Introductory practical session for all project team to introduce artistic methodology.
- November 2012 – baseline evaluation procedures complete
- June 2012 – June 2013 – monthly attendance at ECH/GSTT 'Safe in our Hands' staff meetings
- November 2012 – March 2013 monthly review meetings, minuted with progress assessed against planned outcomes.
- November 2012 – December 2012 Sofie Layton in residence at hospital
- Full team review in April 2013 of material gathered in preparation for its incorporation into quilts.
- Involvement of GSTT team, Evelina Hospital school staff in installation plans
- Installation open to the public for a week July 2013
- Evaluation interviews of key individuals
- July 2013 Discussion event
- January 2014 Research report published and shared with GSTT charity and online







## 9 DISSEMINATION

**Bedside Manners has been the subject of a number of web features:**

Arts in Health South West news item:

<http://www.ahsw.org.uk/news.aspx?id=876>

BKPA – article on website:

<http://www.britishkidney-pa.co.uk/news/76-bedside-manners-arts-project-for-parents-and-families>

Guy's and St Thomas's website:

<http://www.guysandstthomas.nhs.uk/news-and-events/2013-news/20130614-evelina-art.aspx>

Evelina Hospital School website:

<http://www.evelina.southwark.sch.uk/news/article/5257b10bb06d9/>

Anna Ledgard and Sofie Layton's websites:

[www.annaledgard.com](http://www.annaledgard.com) and  
[www.Sofielayton.co.uk](http://www.Sofielayton.co.uk)

The project will also feature in a publication currently in preparation: Ledgard, A. 2014 (IN PRESS) Bedside Manners in Neal, L. Playing for Time, London.





# 10 CREDITS

Punita Sonagra,  
Atul Sonagra,  
Jane O'Leary,  
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Karen Jarvis,  
Dee Garrett,  
Georgie Melville-Ross,  
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Sarah Fisher,  
Daniel Williams,  
Christina Williams

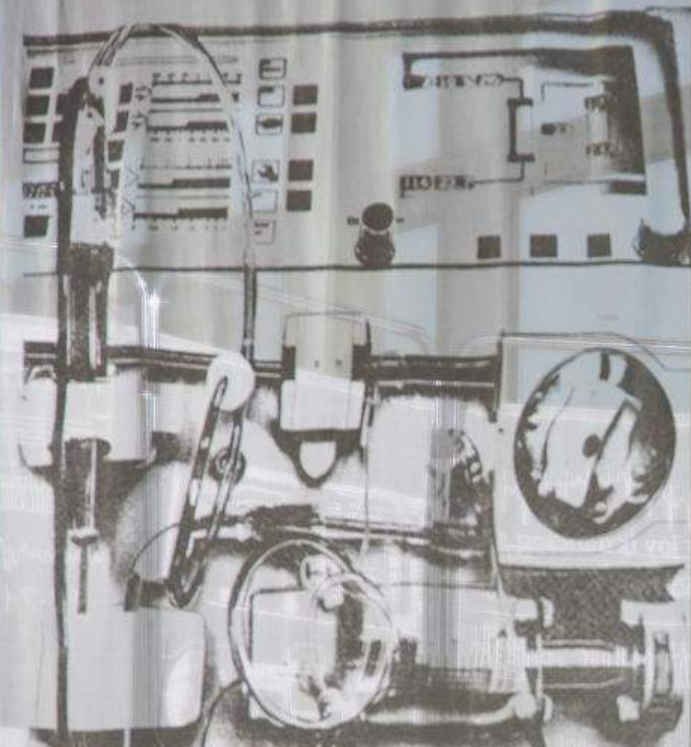
## **Additional collaborators and artists**

Nicola Griffiths,  
Deborah Williams,  
Jon Van Beck,  
Di England,  
Simon Dorman,  
Stephen King,  
Tom Layton with sound by Jules Maxwell

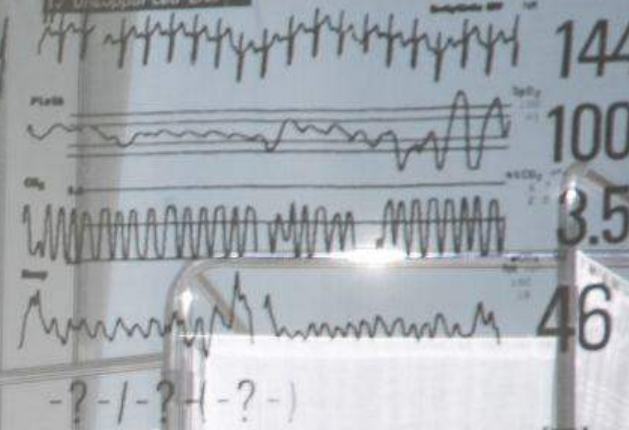
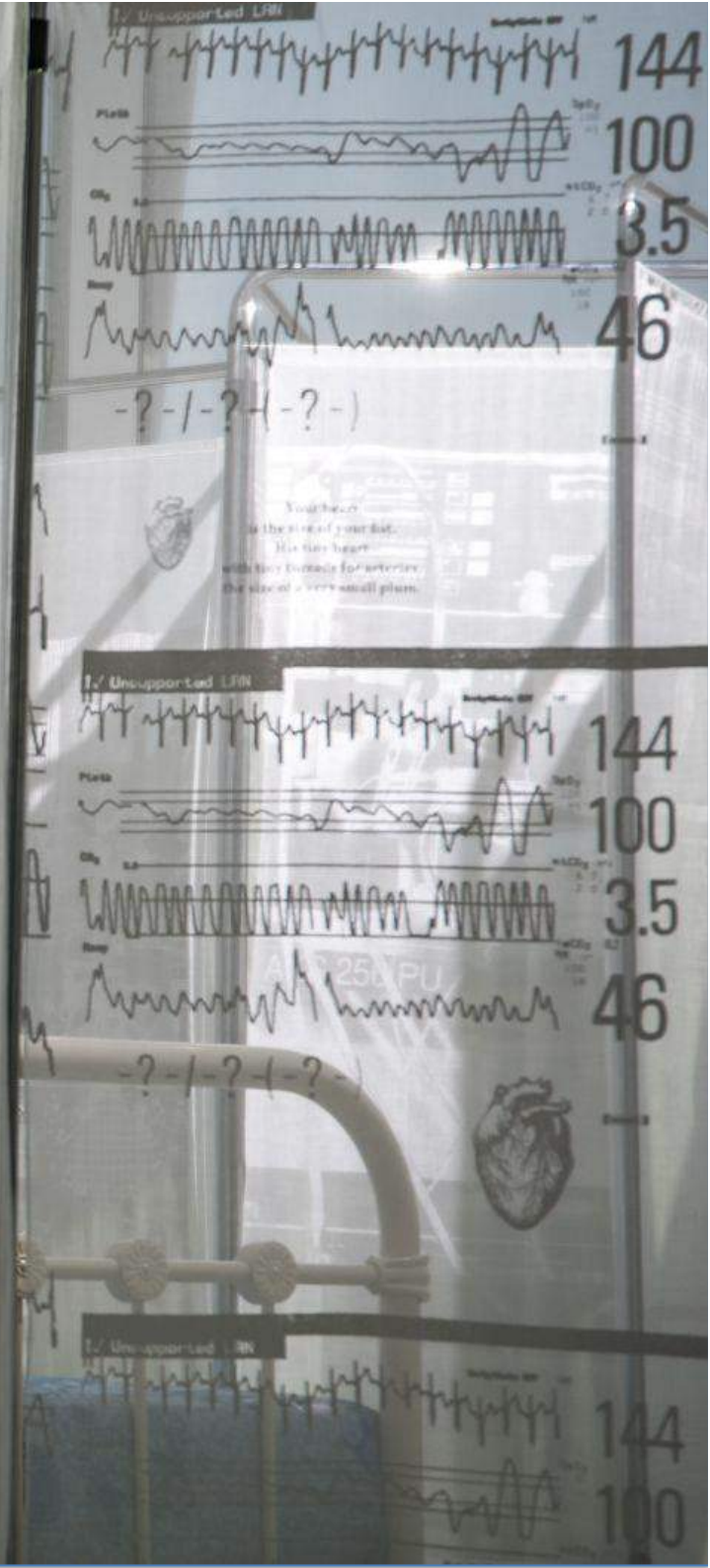
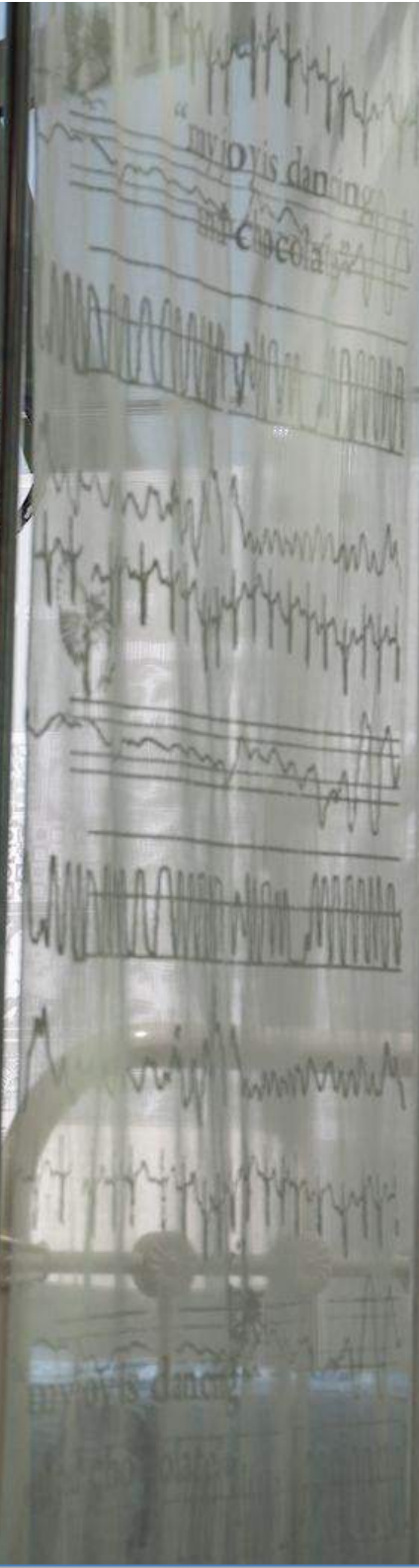
**School liaison:** Russ Venthams, Manuela Beste

**Hospital liaison:** Fiona Lynch, Janet Bennett, Jane Sivyler

**Design/publicity:** Bernard Mordan, Deborah Turner



AKS 250 PU



## 11 REFERENCES

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White, M. (2009) *Arts Development in Community Health: A social tonic*, London: Radcliffe Publishing Ltd.



