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Social Arts Practice with People Living with Serious Illness:

An Evaluation of the Work of Rosetta Life in the West Midlands 2009

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Executive Summary

Social Arts Practice with People living with Serious Illness: Evaluation of Rosetta Life Activities in the West Midlands 2009

1. The aims of this evaluation were to

- evaluate the impact on the health and well being of participants in Rosetta Life activities,
- understand the process and meaning of participating in these activities for the participants and the artists,
- evaluate the artistic process and merit of these activities and the impact of the performances on the audiences

2. The Rosetta Life projects were funded by the National Health Service Pan-Birmingham Palliative Care Network and the Birmingham North and East Primary Care Trust in the West Midlands as part of a wider programme of work implementing aspects of End of Life Care Strategy in raising awareness about living at the end of Life. The Rosetta Life projects were:

- Telling Stories - a partnership with Birmingham Repertory Theatre and Day Hospices in the Birmingham Area based on work developed through workshops. This involved three day hospices each with 6 sessions, plus rehearsals and performances at the Birmingham Rep with participants from one hospice, and filming with participants from another day hospice.

- Seriously Playful - Movement projects with people living with Multiple Sclerosis and Motor Neurone Disease. This resulted in two streams of work Movement in Still Life and Awakening Movement and Imagination.
  This involved 6 sessions in one respite care home, two sessions in a day hospice and x sessions with a support group.

- A feature film length documentary of living with serious illness resulting in a film ‘Night and Day’ This involved filming in the homes of participants and a screening at the Electric Cinema.

- A children’s music making project within paediatric palliative care.

3. The evaluation included three project streams with a more extended case study of the Telling Stories work than the Movement Work and Film. The work with children was not included. The evaluation team used a combination of: observation of Rosetta Life workshops, interviews with hospice participants, staff and artists and an audience survey. The data set of the evaluation included 15 observational sessions of Rosetta Life work in the different settings, 19 individual interviews with staff, participants in the activities and actors, 1 group interview with participants, observation of three performances and an audience survey of two performances.

4. Those involved in Telling Stories in two of the three Day Hospices clearly felt that their participation contributed to their well being. They felt that their voices were heard and that they were able to work with actors and perform in a professional venue. Care needs to be taken to give the staff working with Rosetta Life adequate briefing, preparation and staff development opportunities and to have a key member of staff to liaise with Rosetta Life.

5. The participants taking part in the movement work in the respite care setting enjoyed it; however, others in the day hospice setting did not want to continue taking part. Therefore one size does not fit all. This work with people with MS or MND is experimental with potential but needs development with sensitivity.

6. The artistic process enabled participation in a directed manner that is a reflection of the ethos of RL and its emphasis on artistic quality, at times this was also necessary owing to time and budget constraints. The films and play were developed in partnership with the participants and framed the experiences and aspirations of the people participating in a creative and original way.

7. The audience evaluation showed that the film ‘The Decision’ and the play ‘The Magical Glow of the Co-op’ held their attention and had an impact in stimulating engagement both cognitively and emotionally.

8. There are a number of areas that future partnership work of Rosetta Life could consider developing further in particular in relation to contracting. These are in relation to:

- preparation of staff,
- clarity of parameters and improved communication with partners,
- negotiation of consent for filming and publicity materials,
- support and development of artists working with Rosetta Life,
- importance of ensuring due health and safety in terms of food, comfort and necessary facilities for people who are unwell

9. Consolidating and improving partnership working through clearer contracting would enhance the work of Rosetta Life and the experiences of partnering institutions. Institutions require resourcing and adequate time for staff preparation and training. The support of health professionals based in the institutions is key to the success of the workshops.

10. The work of Rosetta Life was original and did enhance well being for some of the participants involved in the projects. The performed work had a positive impact and was well evaluated by the audience. The Rosetta Life activities are a strand in the ongoing programme of activities on Living Well at the End of Life in the West Midlands as part of the implementation of the End of Life Strategy.

1. Introduction

1.1 Evaluation of Rosetta Life Programme of Work in the West Midlands

This is an independent evaluation by a team of researchers at the University of Warwick of the work of Rosetta Life in the West Midlands during 2009 commissioned by Pan-Birmingham Palliative Care Network through Rosetta Life
The aims of the evaluation were to:

- evaluate the impact on the health and well being of participants in Rosetta Life activities,
- understand the process and meaning of participating in these activities for the participants and the artists,
- evaluate the artistic process and merit of these activities and the impact of the performances on the audiences

Because some programmes had delayed starts, the evaluation fieldwork only began on 22nd January and continued until the end of September 2009. Ethics Approval for the evaluation was given by the Humanities and Social Sciences Research Ethics Committee of the University of Warwick. The researchers had CRB clearance.

1.2 Rosetta Life Work Programme in the West Midlands

Rosetta Life delivers workshops and performances with people living with serious illnesses facilitated by a range of artists nationally and internationally. The programmes proposed by Rosetta Life to the hospices and other partners are based on a track record over some years of what is practicable and effective in unusual working environments. Substantial expertise has been built up. Rosetta Life works in contexts which call for extreme sensitivity to individual and to group experience and feelings.

The partnership projects funded by the NHS in the West Midlands were:

- Telling Stories - a partnership with Birmingham Repertory Theatre and Day Hospices in the Birmingham Area based on work developed through workshops .

- Seriously Playful - Movement projects with people living with Multiple Sclerosis and Motor Neurone Disease known as Seriously Playful. This resulted in two streams of work Movement in Still Life and Awakening Movement and Imagination.

- A feature film length documentary of living with serious illness ‘Night and Day’

- A children’s music making project within paediatric palliative care.

It was agreed that the stream of work with children would not be included in the evaluation owing to the difficulties of conducting research with vulnerable children.

Rosetta Life was initially funded to undertake a new programme of work in the West Midlands for the National Health Service Pan-Birmingham Palliative Care Network. Subsequently the workshops with patients and users in hospices in the region were funded by the Pan-Birmingham Palliative Care Network and the public engagement activities such as theatre performances, and film screenings as part of the Let's Talk about Living campaign were transferred to the Birmingham North and East Primary Care Trust by Rosetta Life. The original proposal was for a programme of work to be delivered between September 2008 and April 2009, but delayed starts meant that it ran beyond this date into the autumn of 2009.

Table 1 Work undertaken in the West Midlands by Rosetta Life

Telling Stories	Hospice A	6 workshops
		4 rehearsals
	Birmingham Rep	2 performances play
Telling Stories	Hospice B	6 sessions?
Telling Stories	Hospice C	6 sessions
	Birmingham Rep	2 screenings Film
Seriously Playful		
Awakening Movement Imagination	Respite Care Home	6 sessions
Still Life	Neurological Group	1 session X sessions
Film Night and Day	Filming in homes Screening Electric Cinema	1 screening

1.3 Background to Rosetta Life

Rosetta Life is a company limited by guarantee and a registered charity governed by its memorandum and articles of association dated 15th March 1999. Until 2009 its head office was in London; it is now located in Oxfordshire.

Rosetta Life's aims are given as:

> The charity's objects and its principal activity is to offer relief to terminally ill people by providing a creative service which enables them to document their lives in whatever form is appropriate to each individual's creative and psychological needs.

(Rosetta Life's Annual Report to the Charity Commission for the Year Ending 28th February 2006, p.13)

Later Annual Reports explain more fully that the charity's objects are:

i) The relief of emotional suffering of persons with terminal illness by providing a creative service which enables individuals to document their lives in whatever form is appropriate to their needs.
ii) To advance the education of the rehabilitation of those who have faced a terminal diagnosis by providing then with access to creative skills which will give then back their self confidence and self esteem.
iii) To advance the education of the public
  - through exhibitions, performances and screenings
  - through training packages for artists, medical and nursing staff

(Rosetta Life's Annual Report to the Charity Commission for the Year Ending 28th February 2008, p.14)

Annual Reports for years ending 2004-2008 show that there have usually been 4 full-time members of staff (except in 2005-06 when just three are listed).

The 2008 Annual Report explains how the organisation also engages freelance creative professionals and works in partnership with hospices:

> The organisation operates as a loose network of artists affiliated through membership to Rosetta Life. Most artists are employed locally by a hospice and have a service contract with Rosetta Life to ensure that the quality and standard of the work is maintained.
>
> Service contracts are issued to all hospices who participate in the Rosetta Life network. Hospices are able to participate in all arts projects run by Rosetta Life and artists have free access to all software and digital arts training undertaken by the charity.

(Annual Report 2008 p.14)

For further background on Rosetta Life previous work see Appendix 1

2. Policy Background

2.1 National Policy

The recent End of Life Strategy published by the Department of Health aims ‘to meet the needs and preferences of people as they approach death’(23:2008) and recognises that ‘many people experience unnecessary physical, psychological and spiritual suffering’ (24:2008). The document states that ‘the strategy aims to bring about a step change in access to high quality care for all people approaching the end of life’ (33:2008) and has ten objectives, some of which are highly pertinent to the work of Rosetta Life.

Three in particular address the focus of Rosetta Life’s work and these are (33:2008)

- To increase public awareness and discussion of death and dying
- To ensure that all people are treated with dignity and respect at the end of their lives
- To ensure that all those approaching the end of life have access to physical, psychological social and spiritual care

2.2 Regional Policy Implementation

In the West Midlands there have been a range of activities undertaken to implement the DoH End of Life Strategy. In 2008, Ipsos-Mori were commissioned to conduct some research through interviews – group and individual and by phone – the findings of which were discussed at the NHS West Midlands Patient, Carer and Public Summit. They identified that there was a need for more information and guidance as well as awareness raising concerning care at the end of life. A West Midlands End of Life Clinical Pathway Group has set out a clear programme for training the workforce in their report (2009) to deliver care in three stages of End of Life Care. These are Living Well at the End of Life, Care in the Last Days of Life and Supporting Carers after Death. Awareness raising and information giving has been undertaken through a range of activities through the Pan Birmingham Palliative Care

Network (www.wellbeingdying.org.uk) as well as through the Birmingham East and North Primary Care Trust. The exhibition on 'Saying the Unsayable': opening a dialogue about living, dying and death took place in Birmingham in July 2009 and the work of Rosetta Life in the West Midlands is part of the programme developed to increase awareness and information on living at the end of life. The Rosetta Life work in hospices was funded by the Pan Birmingham Palliative Care Network and the public engagement aspects were funded by the Birmingham North and East Primary Care Trust.

3. Evaluation – Aims, Design and Data Set

3.1 The aims of the evaluation were to:

1) evaluate the impact on the health and well being of participants in Rosetta Life activities
2) understand the process and meaning of participating in these activities for the participants and the artists
3) evaluate the artistic process and merit of these activities
4) evaluate the impact of the performances on the audience

The first two aims above are primarily discussed in sections 4 and 5. The third aim is presented in section 6 and the final aim in section 7.

3.2 Research Design

The evaluation team took a case study approach to the different activities.
In order to evaluate the work on Telling Stories with the day hospices and the Birmingham Repertory Theatre, the team observed artists working with participants, conducted individual and group interviews with staff, artists and day hospice attendees and undertook a survey of audience members attending performances at the Birmingham Repertory Theatre. The movement projects were evaluated also using case studies with observation of sessions or interviews with staff in two locations. The screening and development of the film was evaluated through reflective interviews and attending the screening. See Appendix 3 for topic guides and consent forms.

The original evaluation design included some methods that the team found in practice at Hospice A to be unrealistic and unsuitable for this group of people living with serious illnesses. The team discussed these difficulties at the advisory group meeting held on17th February 2009 and it was agreed that these methods would not be used. The first was the use of a Quality of Life survey instrument to measure the impact on health and well being for participants in Rosetta Life activities. These instruments were reviewed in detail and it became clear would require adaptation that would not be validated or meaningful. Many items were about physical symptoms or were about daily living that were difficult to link with Rosetta Life work. In addition, administering them took time and effort that it was felt many of the people in these projects were unable to give. They would also have absorbed much valuable fieldwork time, since it would not have been reasonable to ask hospice staff to administer them.

The second method that was not feasible was the planned participatory learning workshops with participants in the Rosetta Life projects. It became clear when piloting this at Hospice A, that participation was very uneven, owing to the different levels of illness, energy and personalities. These patients were not well enough for this interactive approach whereas they were happy to contribute to a group discussion. A more individual approach to participants with more general observation was considered more suitable.

3.3 Data Set

The total data set of the evaluation is summarised in Table 2.

Table 2 Summary of Methods Used for Data Collection

	Hospice A	**Hospice B**	**Residential Care Home**	**Film**	**Non case specific**	**Total**
Interviews						**16**
Users	7 (8)[*]					7
Hospice Staff	3	1 (3)				4
Actors, artists, Rep	3 (5)		2			5
Rosetta Life					2	2
Focus Groups[**]	1 (12)					**1**
Observations (of all workshops with users including rehearsals)	8	3	3	1		**15**
Key informant conversations					3	**3**
Rep performance						
Observation of film, performance and post performance discussion[***]	2					**2**
Post performance surveys	2 (96)					**2**
Film						
Observation of film	1					**1**
Rosetta Life Reports to Charity Commission					5	**5**
Documentation meetings, notes, scripts,					60	**60**

[*] Number in brackets indicates number of people interviewed/surveyed in total. Some interviews included two or three people.

[**] Focus group involved 3 researchers.

[***] Observation of the performance at the Rep involved 3 researchers one night and 2 researchers the other night.

[****] Observation of the film and reception involved 2 researchers.

3.4 Sites of Data Collection

While maintaining the case study approach, the team had to adapt to the unpredictable development and timing of actual projects and often last minute changes of schedule. In the event, more research time was given to one case than to others. This report gives an in-depth account of activity at one site and a lighter touch account of other activities. The reasons are:

- The project at Hospice A was established earlier and gave the team the first fieldwork opportunity to make contact whereas some other projects selected for evaluation began later still or were indeed discontinued.

- Telling Stories completed successfully at Hospice A and provided a suitable point to do a first workshop observation and group discussion. The workshops for preparing the public performance offered many chances for in-depth work with patients, staff and artists.

- Attending the performances offered insights and the chance to do an audience evaluation as well as post-performance interviews. If Hospice B had decided to continue the workshops, the team would have allocated time differently.

- In the movement case study we planned to include an Asian community group, Hospice B's group for people with neurodegenerative conditions and a respite care centre for MS patients. In the event only the last of these ran all the intended sessions and so provided a focus

4. Case study 1: Telling Stories at Hospice A

4.1 Data Collection

The evaluation work at Hospice A ran from 22nd January to 7th July 2009. We observed one workshop where short films of patients were shown then facilitated a group discussion in the afternoon. We observed 3 workshops, two at the hospice and one at the Birmingham Repertory Theatre. There was a brief meeting with the Day Hospice Clinical Manager and we conducted interviews with the day hospice manager, 4 patients and 2 volunteers,

In May and June we observed workshops and rehearsals at the theatre,. 2 researchers attended the first performance and three attended the second. Audience feedback forms were collected. We followed up the impact of the sessions and performances with interviews after the performance of 'The Magical Glow of the Co-op' with the day hospice manager and the other member of staff most directly involved as well as with 6 participants. We interviewed the Rep's director of this production, 3 actors who facilitated the first workshop at the Rep and 4 actors involved in the final show.

4.2 Involvement in Rosetta Life Activities for Staff and Participants

Other activities at this hospice have included occasional art and craft sessions, quizzes and games, limited 'Extend' exercise sessions, sometimes (spontaneous) singing and music events especially around Christmas. However the Rosetta Life project was a much more sustained and ambitious undertaking.

At the start of the project, the probable final outcome – the public performance to an audience at The Door of ‘The Magical Glow of the Co-op’ - was not made clear to everyone. We can speculate about whether people would have participated had they at first known exactly what would be entailed. It may be that projects like this have to take a very open-ended approach at the start, allowing rapport and engagement to develop over time. Our interviews with hospice users suggest this is so, even if it leaves some feeling uneasily ‘in the dark’ at the start. This is the approach which Rosetta Life took, staging the involvement gradually. Certainly these participants grew into the project and engaged more strongly with it as the weeks passed. This was evident even in interviews with those people who took part in the workshops but had not performed or had not been able to attend the performances. So while there was ultimately a ‘community cast’, there was also a fluctuating group of people actively engaged in the process of preparing the production.

At the January focus group discussion with the Warwick team some hospice users recalled how in the first weeks of the project they had real doubts about the point of it. It had taken time for a collective involvement to develop. Another group which attended Hospice A on Fridays had decided not to take up the opportunity. Since the staff and the environment were identical, this illustrates the difficulty of predicting whether a group is likely to become committed and sustain interest. When working with a small group, one or two individuals can sway a group to be involved or withdraw.

4.3 The Role of Staff in Hospice A in the Rosetta Life Project

The hospice became involved initially following several preparatory meetings with Rosetta Life staff, individually with a manager and a physician and also with groups of staff. For the day hospice manager and colleagues, this project fitted with the aim of developing additional therapeutic activities, particularly through the arts, bringing a more holistic element into the service offered to users.

Staff spoke of the benefits it had brought to certain participants, described as fun, laughter and confidence, as well as a ‘distraction’ from illness: ‘something totally different that is still a way of expressing their worries and concerns and exploring them’.

The project grew over time as the day hospice manager recalled:

I wasn’t expecting the way it’s unfolded. I wasn’t expecting so much patient enthusiasm… that’s how we led it because they were so enthusiastic… They wanted to go on stage; they wanted to follow it through. (Day Hospice Manager)

The success of this project and of the public performance is partly due to the strong support offered week by week by staff and volunteers at this hospice. As well as the day hospice manager, an auxiliary nurse was very committed, participating and providing steady continuing support throughout. Yet she too reflected that, while being very impressed initially, she had felt a ‘slight wariness’, associated partly with the professional wish to protect hospice users.

Both took part in the production as part of the ‘chorus’ alongside patients and actors. It obviously gave confidence to participants, and the day hospice manager spoke of this decision primarily as a matter of responsibility: having introduced people to the project, she felt that they should sustain practical support to its conclusion, which meant that both members of staff participated actively as far as possible. The auxiliary nurse had already been filmed in the winter along with patients as part of the

Telling project. The public performances at the theatre on Thursday and Friday evenings followed their usual working day. Though neither took a speaking part, the physical and emotional support given was evident.

The auxiliary nurse spoke of the ‘heightened respect’ for others produced during the project and at the performances:

Everybody was still themselves but with the spotlight on them… I think we helped probably to foster that because they’ve got the trust in [Hospice A], got the trust in us and it’s all worked because of that all round relationship.

There were however unforeseen costs for the institution as the project developed. Staff time and organisation were needed to arrange for participants to travel to workshops and rehearsals. Staff accompanied the Rosetta Life group so on days when they were at Birmingham Repertory Theatre for workshops or rehearsals, other hospice users still had to be cared for on the premises. Reflecting in interview that much had been done ‘on good will’, the day hospice manager prioritised more resources and more pre-planning for any similar project in the future.

Such institutional needs do not necessarily align perfectly with a creative process where the facilitator seeks to keep all possibilities open and ensure that events are ‘patient-led’. There are different understandings of what constitutes ‘patient-led’ amongst health professionals, managers and artists so that this is a further complication in a complex and ambitious programme such as the work of Rosetta Life.

4.4 Professional Development Opportunities for Hospice Staff

The members of staff most directly involved did not make great claims in terms of personal professional development. The project had been demanding and rewarding, showing the benefits for patients and the potential for more work of this sort, but the learning points they spoke of centred mostly on practical or organisational matters for the hospice in the future.

They had been hugely struck by what patients had achieved against the odds and by the ways in which some quieter people really seized this opportunity. The professional learning involved was not in terms of skills or knowledge gained but rather in a general understanding of the potential of such activities.

It was a major commitment for the hospice to get involved in this new venture, which was unpredictable in its likely development and carried risks for both patients and staff. In the later workshop and production phase, hospice staff faced what was described as a ‘crux’ and met to assess whether to continue, given the unforeseen resources/staff investment being made. At this point, as we have heard, it was the enthusiasm of hospice users which helped staff decide to continue.

4.5 Participants’ Views: Being Visible and Giving Voice

In the group and individual interviews at an early stage and after the performance at The Repertory Theatre, almost all participants were clear that their first response to the idea of story-telling was one of caution, for some, scepticism. But, as one explained: ‘then as it went on, it got quite funny and entertaining really’ (E). Another described the first sessions as ‘quite slow really’, and thought the showing of the short films was the first chance ‘to see something worthwhile coming out of it’ (B).

Part way through the project, just after the first workshop at Birmingham Repertory Theatre, one patient captured what several said in interviews and informal conversations:

It is worthwhile in my opinion. It makes people look at us – that we are sick and we can go out and do something….. We look like we've got no energy but by going out we're fulfilling – you don't just sit and feel bored and sorry for yourself. But by going out with this project, it's opened my eyes. (B)

The response of another patient who had a speaking part (and has learning difficulties) was:

I felt really well, happy that it was doing some service for people. (N)

Such comments should be read alongside the audience feedback presented in Appendix 2.

This combination of showing what can be done even when one is very ill, and giving something to other people comes out from one patient who took part in the workshops but could not attend the performances:

It's a mixture of things really. I like taking part in things… and I think if it helps somebody else or somebody benefits from it then I'm happy to go along with it. (K)

She had been taken ill during one of the workshops at the Rep and had to be moved by hospice staff away from the rest of the group, made comfortable and eventually was taken home. In an interview she said:

Where they put me to sit down so I could recover, I could hear a lot of what was going on… I could be sat down with my eyes shut, listening. So that was good. (K)

This (far from perfect) situation does however demonstrate the degree to which those participants who do opt in can really engage with the process. It also shows a huge determination to make the most of such opportunities.

4.6 Meaning and Impact on Well Being for Hospice Users

Even in the pre-performance phase, some participants described how they had developed during the project. One said he was 'a bit more outspoken'. In the storytelling and filming phase he had related in graphic detail an event from the time just after World War Two when he was 18 years old in the RAF and had to deal with a plane crash and a very distressing operational situation. In our interview he commented that he didn't know why he had chosen to talk about this, but:

It got it off me mind a bit. 'Cos as I say I hadn't spoken to anybody about it and it was still in there, you know (G)

Asked later whether he would have recounted this event before being involved in this project, he said:

G: No. I'd have just left it. Kept it to myself, sort of thing. Because I've never spoken about it.
Int: Don't you think people do that quite a lot?
G: Oh, yeh.

Int: About quite big things?
G: They keep it inside instead of. It's a relief when you get it out.

Asked about any effects related to their own well-being, another patient said:

Oh it has helped. It has helped me. It has opened me up. It's like a flower that is closing. And it's open. …. I don't like to be closed in. I like to be – you know – in an open field. (B)

A participant who is very visually impaired as well as very ill, valued the sense that a message was being sent which would help others understand:

It reached everybody, didn't it, from the audience to the people involved in it. And I think it did make people more aware of the sort of things, stumbling blocks if you like, we have to contend with. Not just every now and then, just for a play, but every day. Every day is a challenge and sometimes you don't even want to rise to that challenge. You'd rather just pull the blankets over your head and go back to sleep. But you don't. (K)

Their thoughts about the process of taking part in the project (as distinct from the performance at the theatre) merit attention. One participant had taken part in the workshops but not the performance. Asked what she had got from the experience she said:

A bit of confidence that I could still do things like that because one of the nurses said "They seemed to throw you in at the deep end to start with. And yet you coped so well". … I enjoyed doing it to be honest…. To think that I can still do something. I mean at 90 I was still capable of doing something like that…. I used to go home and talk about it and I don't think they quite believed what really happened. (M)

For another it was:

People telling their stories and their aspirations if you like – what they want to do, and difficult situations. To be absolutely honest .it made me think well – you can do things, you know, you don't have to be limited. You ***can*** *do things. People* ***will*** *help you if you want to do things. (K)*

For another the whole experience including performing had proved uplifting. She had been positive from the start, saying that the preparation process had been 'like a whirlwind' and 'when you got to the actual place it was fun'. The performance itself had been 'brilliant'.

I've seen differences in other people. Because everybody's got their own ailment you know. That's why I don't know how the others feel about it but I feel wonderful.

Asked whether she had felt nervous about the performance, she replied:

B: No, no. It was like a pinch of salt.
Int: Sorry?
B: It was like a pinch of salt – it just melted…. I wasn't shy, no, nothing. It was OK. ***I*** *was OK. Yeh. (A)*

Asked about the effects on her and whether the location mattered, she responded:

I feel more valuable at the Rep. I feel like I'm in something – you know what I mean?.... It makes my life more valuable. I feel like that because you're sick, you can't do something. It makes my life – it makes my eyes open actually (B)

Yet another patient at Hospice A (who did not go to a performance at the Rep) thought that the venue was 'irrelevant', because the play could have been shown anywhere, and possibly at local venues which could be easier for people to get there.

4.7 Access and Participation by Users at Hospice A

What factors enabled this project with Hospice A's Thursday group to complete successfully, when Hospice A's Friday group did not choose to follow through? And how do we distinguish this project from work with a parallel group at Hospice B which chose to withdraw? The participating group were the patients who attended the hospice on a Thursday morning. To opt out of the activity required the participant to be both well enough to walk away from it and bold enough to do so. One patient actively opted out:

C describes herself as a 'butterfly' – not willing to join RL 'Telling' group but observes and moves in and out of the area as it suits her.
Observational Notes 22-1-09

Others were not included if they fell asleep or were too poorly to be involved. There were space constraints as there was no other space at Hospice A to occupy other than the main seating area which was open plan.

When asked whether - if they were in charge of a project like this - they would want to make any changes another time, few interviewees offered any suggestions. Some felt it would be good to have a clearer picture of what would be happening from the start, but one said:

I have to say I'd leave well alone. Because it works in the format that it's in now. There's no pressure, it's enjoyable. It's something you can join in with.
And it's nothing to be scared of. Because some people were a little bit scared. You know, some people – because they are like we ***are****, they're bit scared. You don't want to look a fool. (K)*

This format certainly 'worked' with this group of people involved at Hospice A to produce something which everyone could be proud of and which had value beyond the hospice.

However, this is a complex area, as is clear from the following account where several factors affected the decision not to take part. It shows how an adverse individual experience can make a participant turn away. The reflections of N, a day patient at Hospice A demonstrate the difficulties and sensitivities which must be negotiated at different stages. N explained that at the start of 'Telling Stories', participants were asked to relate a story about a day in their lives to another patient, who would then reciprocate.

I had a significant day in my life which I was prepared to talk about because I thought I was talking to this one person…..

It then emerged that each would retell the other's story to the whole group.

As they went round the circle, I thought "I got the wrong end of the stick" Because I'd majored on the day my husband died… It was a significant day. And other people were talking about mundane things.

Participants then understood that these accounts would be woven into a story for the next session about someone with a terminal illness.

I thought "OK. I can learn something from this".

In fact the storyline provided the next week was missing N's account:

Everybody's contribution was in there except mine. (Pause.) And I didn't question it because I'm not that kind of person.

However, she was disappointed not to have some kind of explanation:

There was a bit of me then that felt a bit sort of "Yuhh"…. I felt "I'm not part of this". And I'd shared something very, very – yes.

Feeling increasingly at odds with events, N's health meant in any case that she was at the hospice only intermittently for a while. On some days when others were at the Repertory Theatre, the group had been 'much depleted'.

Reporting that everyone who had seen the performance had been very positive about it, N concluded:

I thought "Well it didn't work for me but it's done some good somewhere along the line", you know. But I think because I was in and out – but I do think the rejection of my story without any explanation was instrumental in the way I felt about everything.

This patient's effort to explain the various factors which meant that the project was 'not for me' while recognising what others had gained illustrates some of the elements which have to be accommodated in building a cohesive group. It might be that for this person, knowing the plan for the first session at the outset would have prevented the feeling that she had revealed more than she was comfortable with. Similarly, an explanation of why her account was not included might have avoided the complete turn-away. The disruption to her attendance is an inevitable component of these programmes.

These features can be compared with examples from Hospice B where more members of a group decided not to participate.

We therefore signal that the character and personalities of individuals and responsiveness to these are key, alongside the support given by professional staff. The interaction between these two groups and the creative facilitators is a further area for negotiation and compromise.

We have shown how those who do enjoy this type of opportunity gain great benefit even (or perhaps especially) if they have never before had the chance to be involved in this type of collective and creative activity. The auxiliary nurse at Hospice A said she had been especially struck by the responses of more elderly patients (as opposed to those who are more sick). Working with professional actors was mentioned as not just a novelty but a great plus by interviewees.

Initial caution may have been allayed by the positive responses of certain people in this group:

Well I like to be in the limelight. [Laughing] I don't like to be sitting down, you know. I'm a very active lady. So that's the reason why I said "Sitting down here, getting bored – might as well do something that is worthwhile" you know. (B)

Others however do not readily warm to the idea of personal 'sharing' and exposure, especially at a time of great personal stress because of their condition. One uncertainty surrounding any such project is the degree to which individual people feel that they can opt out or that they have enough lea-way to experiment, 'give it a go' but then walk away if they are not wholly comfortable. Here too, personal attitudes varied. Asked why they had decided to take part, two patients (who both continued to the final stage) expressed different views:

You didn't have to but it was one of them things – you were in a group and you thought, em, "Go with the flow" don't you. (E)

I thought it's something else – you can get another outlook on something and you can see different people. You can have a natter or whatever. That's why I decided to give it a try and if I don't like it, I can always drop out. (G)

Some people will always be attracted by the chance to discuss, be interviewed, filmed or recorded. One patient (M) could not actually recall how she got involved but someone had started asking her questions. She noticed he was holding something which she thought was a mobile phone. It turned out that he was recording her voice and he said that it had come through clearly.

This points to the need for very clear introduction to a project: this person might have arrived after that, or might not have taken in the explanation given, or might have been out of the room with hospice staff at the key point where information is given. In this case the surprise of being recorded was a positive one and she was described as 'a natural'.

Juggling how much to spell out at the outset is a judgment which Rosetta Life's artistic director and other facilitators make in any project like this which is potentially long-term, with a possible 'end product' (two performances at a high profile venue). If a project is to be patient-led, then there is always the possibility that patients will walk away.

Any individual may have conflicted feelings: E had once been on television and was cautious but not over-sensitive to the suggestion of storytelling and being filmed. She said that if people had known from the start that they would be filmed, this might have made them more interested. Yet on the scheduled filming date she herself did not come to the day hospice.

I s'pose I was a bit put off because on the day they were coming here to film and we were going to be made up, I didn't come. I wasn't feeling very well.… and I thought "I can't be bothered". 'Cos that's the stage I'm going through at the moment. (E)

E was filmed on another day when 'It was OK'. These comments hint at some of the personal pressures and variable responses which hospice users have to this sort of activity.

Attendance in the Thursday group was bound to fluctuate. People sometimes have other appointments and their health is variable. This is one other uncertainty which Rosetta Life has to accommodate. Despite that, in this group, motivation grew and remained high. The group size was sufficient to maintain progress between January and June. Given the daily difficulties which most participants were coping with, this is strong evidence of the value to them of the work which was going on.

The complexity of working creatively in such environments should not be underestimated. On the one hand, some patients at first went along with the idea simply because it was more interesting than the alternative:

The difference is your time is taken up isn't it so you're more occupied. You're not sitting there with everybody quiet so time goes slow. So it goes a bit quicker when you've got something to do. (E)

The rewards came later, as the comments given above show.

The creative facilitator's role is a major factor in the development of any such project. A participant at Hospice A (who could not attend the performance at the Rep) commented:

A lot of it is down to her. She's very encouraging. She was very patient actually. She's very good. (K)

However there is no guarantee that others can replicate this expertise. Nor is there any guarantee of success as the Hospice B case study shows. Not every facilitator will 'gel' with every potential participant. A style which 'works' with one group may be at odds with another group especially when those involved are in a fragile state physically and/or emotionally.

The dynamics of the group are also critical. In this group there were enough participants who were sufficiently open-minded, experimental or positive about the project for a constructive ambience to develop. The relationship with staff and in particular their participation at different stages reinforced those positive elements.

We would note finally the impact of the experience of working at the hospice and Theatre with actors and a director who proved themselves very responsive to participants' stories and comments and made much of them in a creative way. This happened even though for some this was a quite new area of work and they had little briefing. Our observation of the first workshop with these practitioners logged the laughter and general to and fro while recognising the very serious issues being discussed. There was real comedy in some of the improvised sessions where each patient worked with a hospice user. One said afterwards:

You feel very welcome. Very, very welcome. It's like I'd known them for years. (B)
The films of people telling stories about their lives or important decisions and play were seen by some participants as a way to leave a 'living legacy'. One expressed the hope that it would be a source of memories for her family (26/1/09). The Rosetta Life artists working with participants were also aware of this aspect of the work.

Telling Stories was also carried out in 2 other hospices. In Hospice C, the participants told personal stories to each other and then focused on telling stories about decisions and also tried on hats. This was filmed and screened at the Birmingham Repertory Theatre in a film called 'The Decision' and is discussed in the section on the Artistic Process and reviewed in the audience evaluation. There were no evaluation sessions carried out at Hospice C, but there were observation and interviews conducted at Hospice B where story telling stories and movement sessions took place.

4.8 Rosetta Life - Telling Stories Project at Hospice B

The team conducted 3 observation sessions in March – May 2009 at this Hospice and a debriefing discussion with three hospice staff members. There were no formal interviews with participants. However, in the course of observation, informal conversation on a number of topics took place.

The sessions that were attended were the first, second and fourth sessions of Rosetta Life work at Hospice B with the Thursday group. In the first session there were 8 users, in the second 4 users, and in the fourth session there were 3 users involved and one painting. A Rosetta Life facilitator led the sessions. The first involved individuals telling a story to another member of the group who then told this story to the wider group. The stories were mostly about childhood memories. The facilitator identified themes relating to surviving against all odds, overcoming difficulties. In addition to the users, there was another member of Rosetta Life, a nurse and a complementary therapist present. At the second session, stories were developed around different scenarios with some role playing. Subsequent to this, the staff felt that it would be advisable to work individually with users rather than in a group so at the third session, the facilitator worked with one individual creating a poem as private work for the individual. The original group focus of the activities shifted to working with individuals as a result of the wishes of hospice users and staff.

4.9 Views of Staff on Rosetta Life Telling Stories at Hospice B

There were two members of staff that were key for this group at Hospice B. The first who was the linking member of staff for Rosetta Life was on leave for some time so that the work started two months later than originally planned. She was very supportive of the work. The other member of staff was uneasy about the work and spent time with users who did not want to be involved in the craft activity space. This may have influenced how the Rosetta Life work on Telling Stories at Hospice B was less extensive than at Hospice A, with less participation by users and staff. The sessions were also interrupted between March and May with the Easter holiday period and the hospice was deep-cleaned in April, causing disruption for staff and patients.

Staff member A. The Thursday patient group was initially keen to try it out and there were a couple of sessions and when they realised what was going on, they were no longer keen as a group….. Users started to walk off to the Arts and Crafts room in order to avoid being involved

Staff member B. So we suggested work with individuals. F took this up. T and D also decided to give it a go and then decided it was not for them.
Staff debriefing 6/7/09

The experience of participating in Rosetta Life activities was different for the three users most involved in Hospice B in Story Telling. One worked with the facilitator on writing poems that were personal and reflective and took part in the film Night and Day. Two others attended the play and film at the Birmingham Repertory Theatre and found it upsetting, portraying issues that were too close to their own situation. The Hospice B nurse attended the play and offered them support.

B thought the play was very good and was portrayed well by the patients involved. She thought it was more useful for health professionals. She thought that if patients are going to be invited, they need to be better prepared and better supported.

Similarly during the work with Rosetta Life at the day hospice, there is a need for ongoing support for the users. She had been able to provide this.
Nurse Day Hospice B Staff Debriefing 6/7/09

The clinical nursing director at Hospice B was supportive of Rosetta Life activities but on reflection also felt more support was needed for users.

V would have liked to see the play. She saw 'I Like my Hat 'screened to health professionals last week and loved it. She was clear that being upset is not in itself bad but wondered why there was not more support.
Clinical Nursing Director, Staff Debriefing 6/7/09

The importance of staff support is critical not only in terms of being available to support users and Rosetta Life artists but in terms of understanding the type of work being undertaken. At Hospice B, one of the nurses in the day hospice was not in sympathy with the work of Rosetta Life and worked with users in the Craft area during Rosetta Life activities. She said :

I will put my hand up and say that I did not agree with the work of Rosetta Life. I was disturbed by it and carried it with me for a while.

The clinical nursing director, reflecting on Rosetta Life activity at Hospice B, felt that there had needed to be more preparation of both staff and users. She was clear that the Hospice had been involved in other art projects and was not hostile to this type of endeavour.

Hospice B is keen on arts and is involved with a big photographic project with the IKON gallery…... Staff had four preparatory meetings with IKON staff and developed clear ground rules. The day hospice was turned into a photographic studio for a day. The users are going to the IKON gallery to see the photographs and discuss them. The Art world and the clinical world are very different – and we need to have a dialogue in order to work together that covers not only ground rules but choice of patients, pitch etc.
Clinical Nursing Director Hospice B 6/7/09

In addition to feeling that more preparation time was necessary, the particular demographic mix at this Hospice was felt to be a likely factor.

Patients are often not 'arty' and do not know what to expect. The demography of the patients is that they are from a lower social group, greater ethnic mix, from inner city areas and often not theatre goers. This is something noticed by staff who come here from other hospices.
Clinical Nursing Director 6/7/09

Therefore the experience for staff and users of being involved with Story Telling varied between Hospice A and B. Staff preparation and support is clearly key and is required to underpin the viability and success of the partnership working. One size clearly does not fit all owing to the diversity of users, and particular conditions at the Day Hospices.

To what extent was the work of Rosetta Life 'patient led' and owned by the participants?. The parameters are set by the Rosetta Life facilitators in terms of the type of activity eg. Telling Stories and the theme sometimes identified eg. Decisions. The workshops leading to a performance or film were also led by Rosetta Life and part of the work programme. Within this participants develop their own unique stories and roles. The work was developed through partnership with the participants within given parameters of time, and type of activity.

5. Case Study 2: Seriously Playful: Movement in Still Life and Awakening Movement and the Imagination

5.1 Background to Seriously Playful

The work with movement followed on from previous Wellcome Trust funding on Movement in Still Life to Rosetta Life. The movement workshops took place in three sites – a group for people with Motor Neurone Disease (MND) of Asian origin, a neurodegenerative group for people with MND and Multiple Sclerosis (MS) at Hospice B, and a residential care facility for people with MS. The evaluation focused on the last two of the three sites and did not include the first because this group changed premises, was not regular in its meetings and did not complete the movement sessions with Rosetta Life. In addition, awareness raising workshops for staff in the different Primary Care Trusts were held concerning movement work with people with MND and MS, and subsequently staff have been referring patients to Rosetta Life for individual one to one movement work. Evaluation Feedback from these workshops has been collected by Rosetta Life.

There were three movement practitioners involved in this work with different backgrounds. In Hospice B, two artists of Rosetta Life who had worked together in the previous Movement in Still Life project did the sessions together. A movement practitioner with a background in working with young people with learning difficulties worked in the residential care facility. These two settings were very different in ethos and participants and so will be set out separately. There was no observation of sessions in Hospice B, but a discussion was held about this activity with staff after the end of this work. In the residential care setting, three observations were conducted in June and July and the facilitator was interviewed.

This work is innovative and exploratory as well as sensitive. Using touch and imagination, it involves working with people who have lost mobility and movement.

5.2 Seriously Playful: Awakening Movement and Imagination at the Residential Home for People with MS

These movement sessions were delivered on a Sunday afternoon from 3pm – 4pm by a movement specialist who had experience in working with people living with physical and mental difficulties. Three sessions were observed by different members of the team. Conversations were held with different staff members.

There was generally a mixture of residents and people staying for a week or two for respite care, some of whom had arrived the day before. In addition, there was usually a student nurse with the group. The sessions were held in a beautiful circular room with large windows overlooking a meadow and garden and a domed ceiling that was timbered. The chairs were in a conservatory style. The participants were all in specialised wheelchairs.

By the end of the session people were thirsty and some water could have been provided. There was no staff support for gathering people together in the room and the movement practitioner would arrive half an hour before and recruit and move people to the circular room. At the end of the session again there was a lack of staff help until requested to push chairs over to the eating area.

The session described in the artistic process section involved moving fingers and toes or imagining the movement if one was not able to do so. The telling of stories triggered by objects often involved memories of movement such as horse grooming, riding, cycling, walking dogs, walking on beaches and people were encouraged to remember and sometimes make small movements if they could. Also some touching – hand holding, stroking was encouraged. Soft music was played in the background. Participation varied owing to the physical state of the participants and the different members of the group each week apart from the three residents.

At the end of the session on 14th June, the movement specialist asked participants to describe how they felt and these are the adjectives that each used (the commas indicate each person's contribution):

" *Relaxed, relaxed, blue sky, tired, sleepy, breathing, interaction super - good to meet everyone, meeting people is part of being here – better than going up and down the corridor on your own, tired and relaxed, relaxed and happy"*
14/6/09

This indicates clearly that the participants enjoyed this session and that it contributed to their well-being. The session was held on a Sunday afternoon when the Leisure staff were not on duty since they only cover the weekdays.
There is potential however, for this type of session to be included as a mainstream activity and to train staff to deliver it or support it.

5.3 Seriously Playful: Movement in Still Life with the Neurodegenerative Group at Hospice B

This group had been meeting for 12 months with a core and had recently been joined by some new people at Hospice B on Tuesdays. They had conditions that were progressing slowly, either Multiple Sclerosis or Motor Neurone Disease. They sometimes took a break from the group and the establishment of this group was part of the hospice opening its doors to other conditions. They had one session of movement with RL facilitators to which there was a diversity of reactions to the first movement workshop with some people being positive and others not so much. The group declined to continue with this in the second week and it was felt by the hospice staff that one or two of the core members of the group, led opinion in the decision not to continue with the activity.

The clinical nursing director felt that there needed to be more preparation with the artists in terms of briefing and regretted that there was no way of working through the difficulties:

' I felt that there needed to be more preparation of the facilitators prior to this work with the hospice staff and patients in terms of briefing them about the diseases and stages of the disease and the people involved so that they could be more informed, and setting up and working out clear ground rules for the group.ie. ok to be upset, support, confidentiality,
Clinical Nursing Director Hospice B

The movement sessions were successful in one setting but not in another. It is difficult to engage people with differing levels of limited mobility and capacities. The work as conducted at the Residential Facility allowed people to engage at whatever level they could, and this is probably the way forward in this interesting area of work that could be expanded.

6. Artistic Process

This section of the report addresses one of the aims of the evaluation, namely to evaluate the artistic process and merit of Rosetta Life activities in the West Midlands.

6.1 Data Collection

Data were gathered for this through observation of sessions, rehearsals and performances and interviews with a range of artists and actors.

Table 3 Summary of Observations and Interviews to evaluate the Artistic Process

Observation sessions	**16 sessions in total**
Sessions Hospice A	3
Sessions and rehearsals at the Repertory Theatre	6
Rehearsals	2
Performances at the Repertory Theatre	2
Session at Residential facility	1
Screening of Film at the Electric Cinema	1
Interviews	8 interviews in total one of which with 4 people
Individual Interviews with workshop actors	2
Group interview with performance actors	1 x 4 actors
Movement practitioner	1
Director of Education Birmingham Repertory Theatre	1
Director of Media, Rosetta Life	1
Artistic Director Rosetta Life	2

Evidence from case studies of developing practice in community based arts indicate that, while participation is greatly to be encouraged, where art is concerned, the attitude that ‘anything goes’ can be detrimental to the success of a project. Participants in the best projects placed great emphasis on the importance of the quality of outcomes as well as the benefits of the process of involvement. (Arts for Health 2000 :2). This is clearly an approach shared by the Artistic Director of Rosetta Life.

Our process is about enabling every person to perform themselves as a story and find a way to hold that aesthetically and looking at what the aesthetic practices are to enable that to have a professionalism that is shocking and surprising because of the authenticity of the characters on the stage.
Artistic Director RL 15/5/09

Rosetta Life seeks to promote the highest levels of artistic aesthetic and gives community participants opportunities to work with artists of experience and standing in their fields. The charity seeks to work with interesting and sometimes well known artists many of whom have formally trained in their fields. The three projects that are evaluated for this report are no exception.

All the printed publicity material produced by Rosetta Life is of a high standard of design and production. Their web pages and publicity material are all professionally produced and linked under a wide span of different projects. The artistic work is undertaken in challenging conditions and is original, interesting and impressive in many ways. (http://www.rosettalife.org/content/about/)

6.2 Artistic Process – Telling Stories Phase One

The Telling Stories stream of work involved a team of artists and actors working in partnership with both the Birmingham Repertory Theatre and Day Hospices. The development work involved the Artistic Director and Film Producer of Rosetta Life, a movement and dance artist, and a make up artist. The people involved from the Birmingham Repertory Theatre were the Associate Director for Learning and Participation, a Dramaturg, Free-lance Actors with experience in community arts recruited by the theatre**,** the resident Stage Company Manager and Technical and Front of House Support.
The project was facilitated through a number of distinct phases.

1. One to one work in the hospice led by the Rosetta Life Artistic Director

2. Showing of a film of the participants telling their stories in the hospice

3. Group workshops facilitated by the theatre director and actors from the Birmingham Repertory Theatre in the hospice and then subsequently at the theatre

4. Rehearsals in the studio theatre space The Door at the Birmingham Rep led by Theatre Director

5. Performances at The Birmingham Rep directed by the Theatre Director

Initially the Artistic Director worked with individuals and then with people as a group. She explained in an interview how she prefers to nurture individuals by first working with them on a one-to-one basis, which enables her to get to know people better. It is less threatening than having a facilitator lead a whole group of people from the front especially if there is nowhere for participants to go and this method allows the Artistic Facilitator to work with individuals and to get to know the participants.

She started with them telling each other stories and then recounting others stories back to the group. When it came to filming, a different person did the filming. He prompted them to tell stories with questions from behind the camera. They had not felt sure of taking part at the outset, but now could see where the project was going and hoped it would succeed.
Observational notes 26/1/09

6.3 Telling Stories Phase Two

In the second phase the group came together to view themselves telling stories on film. The film had been made in the previous weeks. They discussed and fed back on the stories with the Artistic Facilitator leading the whole group and guiding the process. Seven stories were reported back at this session. The stories were an eclectic mix and varied from being quite amusing to being difficult to listen to as one participant only wanted to talk about her condition. The first story of a patient (A) who wishes to go to America was framed as being about the choices one makes. This became very upsetting for (A) who was very tearful, perhaps as her state of health on the day of the viewing indicated that it seemed unlikely that distance travel was a possibility for her. Each film was shown with linking remarks made by the Artistic Facilitator who explained that the story to be told in the theatre would be the story of one woman and that she was looking for ways of linking themes in the stories about choice and living well.

The films were professionally shot from a broadcast standard camera and both sound and visual qualities were highly professional. There was considerable jesting during the session about the importance of the makeup that had hidden a few blemishes and showed those filmed at their best! It seemed as if the make-up session was enjoyed by all the participants and one of the aspects of the activity to which they most frequently returned. The films were occasionally roughly edited but these story portraits were not films for public gaze but for the benefit of the workshop.

The public space in which the group was held influenced the dynamics of the group and it may have influenced people's responses. However this setting was comfortable for participants. Observation Notes 22-1-09

It was a well thought through notion to bring the group together in this way. The first seeds of group bonding became apparent as participants chatted and shared their responses in a relaxed and easy manner. The stories were revealing without giving away too much personal information with the exception of one film which focussed entirely on how ill and distressed the participant was. This was the only participant to talk about her condition.

The fluidity of the group did mean that one person who had told a story was not present and a couple of people who had not been filmed were present. This did present issues about inclusion; on some levels the cohesiveness of the group was impaired and the wisdom of showing the film of the person who was not present could be questioned.

There were a range of comments made during the discussion a sample of which are below which indicate that storytelling prompted reflection in a positive way.

People's stories were like layers of elastic bands forming this solid whole like a golf ball. Not like a tennis ball which is hollow in the middle.

Being here takes your thoughts from what is happening to you.

The moral of the story is: don't count the breaths you take, count the moments that take your breath away.
Group discussion 22/1/09

There is a fine line between taking people into those places they cannot easily face in a workshop context to elicit the truth of a situation and the vulnerability of this group so that careful facilitation is required. Time and financial constraints do not really allow for planned creative partnership and the collaborative expertise of both partners to exploit the potential of such work. Deeper planning between the artist and hospice with opportunities for brokered reflection would be desirable. These issues are clearly understood by the Artistic Director who works within these constraints:

More planning, you never enough planning time with small budgets, very small and time with staff…
Artistic Director 15/5/09

6.4 Telling Stories Phase Three - Workshops and Rehearsals

The third phase consisted of the workshops and rehearsals. There were workshops at the hospice with the Associate Director from the Birmingham Rep and an actor, and three workshops and two rehearsals at the Rep with the professional actors.

It is not possible at this funding level to retain a company of actors over such a length of time however a number of the actors were re-engaged so that several worked with the group at least twice. By the time rehearsals started one of the company of four had worked with the group before. This was advantageous and was a bridge to a relaxed relationship with the other actors quickly being formed.

The actors received calls either directly or through their agents a few days before the workshop. They knew that it involved working with people who were in a hospice but other than that the discovery of what was entailed was an ongoing process during the workshop.

They were given the outline scenario someone who was very ill, dying, having a family reunion. The actors said that they were very experienced and it didn't present any problems having little background information and agreed it could be an advantage in many ways helping to tell a story without any preconceptions of which way it would go. They said that they were used to getting to know people very quickly.
Interview notes 30/4/09

Our view as external evaluators having observed workshops in Hospice A and at the Birmingham Rep, is that the commissioned actors were responding to particular and sensitive circumstances. In the light of this, they require adequate briefing ahead of a session with people in a fragile situation. With the support of hospice staff and volunteers, patients made huge efforts to meet this commitment and they too deserve that the people they meet will have some general understanding of their difficulties.

The Theatre facilitated two workshops in the hospice and three workshops at a venue in the Theatre.

The Director showed me the prompts and explained how he was going to use them. He explained that he was going to run a typical DIE (Drama in Education session) to encourage the patients to participate in the story making process. The dramaturg was going to take notes and observe.
Observation notes12/3/09

One actor was used for this session and she worked well though sometimes had problems positioning herself so that all could see and hear her in the space. The actor took a number of roles indicated by the Theatre Director B and supported by Rosetta Life's Artistic Director. The actor was competent although this group might have related more closely to an actor who was closer in age to the group average.

The choice of actors for the final production was exemplary with actors chosen both for their ability to perform but also for their experience of working in community contexts. None of the actors had worked with people in this older age group before and none with people with life limiting illness. They became close to the group with two of them visiting the hospice after the performance

The Group warmed up and all were asked to contribute so the sense of being allowed to have a voice, being listened to was established as well as an amusing way to introduce people to each other.
Observation Notes 12/3/09

The Theatre Director ran very successful workshops and did much to enable the group. He gave them ownership of the material and was hearing and visual impairment aware. He was adept at drawing out the more reticent members and controlling those who tended to dominate thus ensuring that all opinions presented for facilitation were heard.

The workshop sessions were split into the playing out of scenarios by the actors who were subjected to hot seating (staying in role and being questioned about their actions) to Forum Theatre style replaying. Forum Theatre enables the members of the workshop to change the responses of the actors to the given situation (Boal 1979). The second half of the workshop was that of group drama work to develop the skills of the participants. Participants would be given a role developed from the scenario for example interviewing a new carer. The participants would then be in role as the service users.

All the participants took pride in their work and the group had some control of the medium in which they sought to express themselves.

The group was noticeably more adept at building a character after the experience at the Rep two weeks previously. Also the Theatre Director was highly skilled at seamlessly moving the questions from himself to the participants. Observation Notes 12/3/09

This progression and skills development in people for whom life has been contracting rather than expanding should not be overlooked.

The actors did not know they were going to be filmed during the workshops and were not happy that they had not been asked.

I asked if they were aware it was going to be filmed and documented. They said that they didn't know that they were going to be filmed and one actor said that the film diminished the quality of the workshop; the group including ourselves would have been freer without it.
Observation notes 12/03/09

It is generally useful to record aspects of a workshop especially if, in this case it is the basis for a production. The digital vision and living legacy of the work of Rosetta Life means that work in process is often filmed. Permission to film needs to be requested at all stages particularly when working with people who may be unwell and so may not attend every session.

The actors reflected on the experience of working in workshops and rehearsals with this group:

They both agreed that the Rep Director was a highly skilled practitioner who knew what he was doing and they thought that the session had gone really well. One actor said that he did feel that there was a tension between the brief and the participants in that the participants were not necessarily considering story through the lens of someone dying but making responses as themselves, not with the label of 'very ill' placed upon them. He thought quite hard about actually saying 'I am dying' even though that was his brief. Another actor also said that he was aware of making the work entertaining and not being true to the story or situation and he was aware of that tension as well. Interview Notes Group interview with actors 30/4/09

By the time the group attended the first session at the theatre there was a real sense of excitement and expectation. The sessions took place in the Centenary Suite as this had suitable access for the participants. This room is not managed by the theatre as it falls under the aegis of the Conference Centre although it is in the theatre building.

Rosetta Life agreed to pay the theatre for space and staff costs. Frustratingly the Centenary Suite which was used for rehearsal belongs to the Conference Centre (next door) and had to be paid for. There was no suitable space with disability access for rehearsal in the theatre as such.
Interview 28/5/09 http://www.birmingham-rep.co.uk/about/library-of-birmingham/faqs/ (improvements to the theatre)

The group was supported by staff and volunteers from the hospice. The staff and volunteers morphed into their performance roles partly on the necessary pretext of supporting their patients on stage but also for the most part they were quite keen to share this experience. Any reluctance at the onset was dispelled after the first theatre based workshop. This worked extremely well and ensured that the whole project was a shared experience for the hospice; it also served the play to advantage as the swelled ranks of the choric ensemble were able to span the stage.

Performance projects that have a production outcome are by their very nature highly time consuming. The Artistic Director of Rosetta Life was very aware of the complexities and difficulties of this type of project with people who were unwell and emphasised the importance of the fluidity of the project to all the partners – the hospice, and the theatre.

……things are not going happen in a prescriptive way and the cast may perform and they may not and let's evaluate it at the end of four months and see what we think will happen and take stock then. I can be that fluid and I'm asking you to be, if you can't then we'll go to a different venue because I don't think the participants get enough out of it unless we can be more fluid.
Interview Artistic Director Rosetta Life 30/08/09

There were acknowledged tensions between the theatre and Rosetta Life. Large Theatres have to keep to their scheduling as each department works to a budget which impacts on time and resources. The fluidity of the work of Rosetta Life is challenging to accommodate within such an institution. It is hoped that with the new build at The Rep the disabled access issues will be addressed and that the freeing up of The Door for more community projects and the integration of more outreach work from the theatre would mean that such work might continue.

The Theatre Director understood well the complexities and uncertainties that are part of community arts practice. In this instance the Director managed the fluidity and uncertainty by not advertising the play in the public programme or on the website, the production was promoted as private performances and billed as a rehearsed reading.

I am committed to community partnership and I dealt with the prickliness of the management by telling them it was a rehearsed reading and not a performance. The people in the organisation then felt more comfortable. I have quite a high tolerance for uncertainty and things coming together on the last day; the cast not being around for a polished performance. But this was more than a rehearsed reading.
Theatre Director Interview 4/6/09

The play was submitted to The Rep later than originally scheduled by Rosetta Life and the Theatre Dramaturg had little impact on it. A publicly funded theatre such as The Rep would be unlikely to promote a community project by an unknown group (to them). Rosetta Life had worked in The Hampstead Theatre and Riverside but these were hires of a venue not co-productions, with all that this implies in terms of collaboration, coordination and communication.

There was some confusion between the theatre team and Rosetta Life concerning roles, timeframes and deliverables as well as the fluidity of developing this type of work. There was nervousness from the Theatre team so that they required reassurance. Although a formal contract for such partnerships is not necessary a 'letter of understanding' with both the production responsibilities and the artistic vision committed to paper would be helpful in future. Such a document could be amended as a project develops and might have been helpful. As previous work has shown:

…projects need sufficient time for planning, for building successful participatory methodologies and creating robust models for partnership working. (Arts and Health 1999:3)

In summary, the participants in the project involved people attending or working at two day hospices. In Hospice A, patients, staff and volunteers were involved in a performance as a community cast performing alongside a team of four professional actors. The production was professionally directed and co-produced by Rosetta Life in partnership with the Birmingham Repertory Theatre. Rosetta Life was the key producing partner, initiating the project, planning and managing timescales, locations, workshops and performance content. The Repertory Theatre offered general expertise and a professional performance venue, professional actors, a Dramaturg, Stage Manager, technical support and a Stage Director.

6.5 Telling Stories Phase Four: Screening of 'The Decision' and Performance of 'The Magical Glow of the Co-op'

The final phase of the process was the performance itself, shown at The Door, the Birmingham Repertory Theatre's studio space over two consecutive evenings to a full house on both nights. The audience was a combination of invited friends and relatives and staff as well as others reached through Rosetta Life marketing and networks.

The evening began with a short film, 'The Decision*'* featuring performers from Hospice C . After sessions at the day hospice telling stories of decisions they had made in their lives, they were professionally filmed by Rosetta Life and were facilitated to share on film their stories. They also were filmed trying on hats to frame themselves and their lives in terms of 'this is me' with laughter and stories. This showed them having a laugh but also being themselves as people unrelated to illness. This film acted as a prologue to the live performance of 'The Magical Glow of the Co-op'. It was a wonderfully insightful framing that enabled the audience to deeply engage with the reality of those with life limiting illness. This film despite its short length was deeply memorable and through the stimulus of inviting the performers to try on a variety of hats and by off screen facilitation, posing the question of an important decision that they had made in their lives, the film performers explored their identity, not in terms of people who were ill and dying but of the vibrancy of their living.

The play that followed was professionally produced by the theatre and was performed with an ensemble community cast from Hospice A and a cast of four professional actors. It was drawn from the workshop scenarios as resource material and text was created by the Artistic Director of Rosetta Life. The play text was further worked in rehearsal with the professional cast and director.

The play was called 'The Magical Glow of the Co-op' after a comment made by one of the participants describing the difficulties that have to be surmounted simply to reach the shops. The play covered the key issue explored in the workshop of a family member, a daughter who was in denial about the impending death of her father. The play focussed on 'Alan' and how he managed the choices that he wanted to make facing death against the different demands of his family. Kathleen still thinks that her father would be 'better' if he came back to Ireland. The community company were cast as extended members of the family, with one of the community cast playing a carer. The community cast framed the back of the stage space in an embracing choric arc. They opened the piece with a wonderfully choreographed moment of carer and cared for as each cast member engaged through look and touch with each other. This motif was repeated later in the play with a slight variant. The choric work of the community cast was moving and performed with great integrity. The play was less than an hour in length; however the audience engaged with the story, that of a middle aged man who was facing his own increasing ill health. There was a post show discussion facilitated by both the Birmingham Repertory director and the Artistic Director of Rosetta Life. Both the performances and the audience discussion were filmed. The audience were photographed entering the Door and during the discussion including when people asking questions were upset. Permission was not sought from the audience for the filming prior to it taking place. This could be addressed by requesting permission prior to the performance from the audience.

The age of the participants of the 'Magical Glow of the Co-op' ranged from two participants in their 40's, to one participant in her 90's. The other two hospice patients were in their 70's all were suffering from life limiting illness though one participant in remission from cancer treatment remained part of the project. The participatory group also consisted of staff from the hospice both volunteers and professional staff. Participant attendance in community projects is always fluid and affected by factors such as cost, health, and other personal circumstances. For the day hospice users the key issue was that of their health and general ability to cope with the workshops, rehearsals and performances. Some participants were very ill, sometimes in pain and having difficulty breathing or moving around. Others appeared superficially well; some were very elderly. One participant had learning difficulties.

The actors placed great emphasis on the benefits of the process of involvement:
I have been moved by this work more than any other acting job. I got emotional during rehearsal and I talked with L who has her own specific experience and she said, you have gone through something. This has settled something for me personally.
D and L Professional actors, Interview notes 4/6/09

6.6 Seriously Playful: Awakening Movement and Imagination and Movement in Still Life

This element of the Rosetta Life's work was undertaken in three locations – Hospice B, an Asian group of people with Motor Neurone Disease (MND)and their carers and a residential home for people with Multiple Sclerosis (MS). The artistic evaluation is based only on observing the last setting. Three sessions were observed by the research team with the artistic evaluator present at one.

This project involved 6 workshops at a purpose built residential unit for people with (MS) where the participants were both temporary and permanent residents. The workshops enabled the patients to imagine movement or to make small movements in the framework of different narratives offered by the facilitator.

On a table, waist height in the centre of the room [the artist] has put out a variety of different objects. They are set on a table with an interesting cloth underneath and it looks inviting. She invites the participants to gather round, move their wheelchairs closer to the table.

The large bright space was transformed and enhanced with this enticing table of intriguingly displayed hand sized eclectic objects and with soft music playing in the background. The facilitator was left to recruit the group herself. The nature of the work is difficult to describe to participants as it seems incongruous to suggest to people with very limited movement that they should attend a movement workshop.

The facilitator had great difficulty describing what she was going to do, though she won people over with her nice gentle demeanour and most came I think because nothing else was happening and just to give it a go. Observational notes 1/7/09

The session consisted of limited group movement prompted by the movement facilitator using a prompt as stimulus and visualised movement and storytelling prompted by objects that would lead to movement and also could be recorded on paper as a picture. This worked extremely well and all the participants who could, picked up objects and those who had speech told stories and those who could move enjoyed the opportunity to do so in a group in an imagined context, such as all falling onto a feather bed and those who couldn't responded in their imagination. It was a highly liberating session for all participants even those with almost no movement at all.

She then asked people to visualise movement in the toes. This generated considerable interest with B and S both describing that they could 'feel 'their toes moving even though they weren't. One mentioned that she tried this sometimes at night to see if she could 'feel' her toes.
Observational Notes 1/7/09

This workshop was an example of best practice in that it was utterly inclusive in one of the most challenging situations. All participants had ownership of the outcomes in that the stories and choice of stimulus were made by them. There was a sense of shared experience even after only one hour and of having taken a journey together which was both creative and deeply relaxing. It was clear that the participants could not have managed more than an hour though one also sensed that several would have liked the session to continue or have the opportunity to attend on another occasion.

6.7 ‘Night and Day’: A Documentary Film About Living with Life-Threatening Illness Around the Clock

This was directed edited and produced by the Director of Media of Rosetta Life and featured day patients who had been referred from hospices across Birmingham. Night and Day is a professional enterprise with the documentary material drawn from patients who attend various day hospices or have attended a hospice. The artistic evaluator interviewed the Director and was present at a screening of the film at the Electric Cinema. In initial team discussions agreement had been reached that attendance at the film making stage might not be desirable owing to the filming taking place in participants’ homes.

I’m making this film….in the Birmingham area with six or eight people who are living with life threatening illness and their carers and the purpose of the film really is to open a window onto the experience of those living with life threatening illness at home and simply to sort of gain that reality into the minds and attention of the people of the West Midlands.
Director of Media 15/5/09

I know about listening and I know about identifying the salient if you like so my job here is to watch out for and identify the salient in any old conversation or anything that might be happening and I see it and I take, I just hold it and I tease it and then you’re teasing and beginning to help the other person see that we have something here that we could be making and exploring and giving expression to…. of enabling someone to find a voice, create a voice in the sense that it’s a creative intervention that’s going on and it’s about finding that bit of gold.
Director of Media 15/5/09

Now what happens has involved them talking about the nature of their loss and their experience of grief, this is at the centre of it now with my counsellor/film makers hat on and I call the process sometimes counselling on camera because I think that I’m talking to someone and what I’ve got in mind when the camera is turning is making a good film and I’m always honest about that, but in order to do so I need to be just really totally honest with what people are saying and with what we’re addressing.
Director of Media 15/5/09

This is an experienced documentary film maker who has for many years worked with the BBC. His 45min film Night and Day was shown at The Electric Cinema Birmingham to an invited audience. The film shows six different stories of people living with dying in Birmingham. It is a story of their resilience and ordinariness. They are all remarkably candid and tell of their fear and courage in equal measure. The showing at The Electric Cinema was followed by a champagne launch and supper of the ‘Let’s Talk about Living’ campaign at the Radisson Hotel in Birmingham at which the work of Rosetta Life was further explained. The film has the potential to be used both as a teaching/training particularly as short vignettes as is planned.

6.8 Artistic Process Summary

The most successful examples of art-based intervention are driven by the intuition and creative energy of an individual or a partnership which acts as impetus for the project’s conception, development and delivery. In this respect, dependence on key players has strong implications when considering sustainability. The founders of Rosetta Life have a distinctive partnership. With the expansion of their work to include more areas and institutions, more artists are involved and it is important for sustainability to develop shared ways of working and approaches with them through ongoing professional development sessions with opportunities for reflection.

The work of Rosetta Life in the West Midlands has been highly original and the process of involvement for both creative professionals and hospice participants and staff was meaningful to them. The section on audience evaluation will show that the performances were valued very positively and enthusiastically. The main issues for future work to be considered are:

1. Clearer partnership arrangements with both hospices and theatres in relation to contracting and ways of working
2. Development of professional support and development of artists involved
3. Clearer negotiation of consent when filming actors or audiences at performances

7. Audience Evaluation of the Play 'The Magical Glow of the Co-op' and the Film 'The Decision'

There were two screenings of the film 'The Decision' followed by two performances of 'The Magical Glow of the Co-op' held at the Birmingham Repertory Theatre at the Door, the studio theatre. In addition to observing the performances and audience discussion, the audience were given an evaluation form and 96 completed forms were handed in. The full report is given in Appendix 2 .

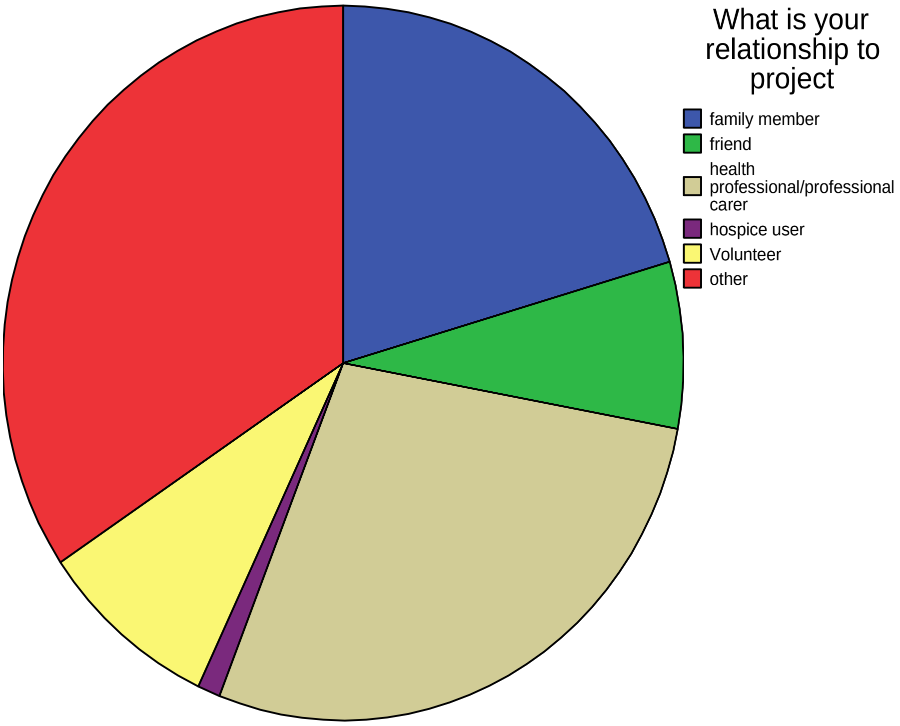
7.1 The Audience

72% of the audience identified themselves as theatregoers and only 13% had been involved directly with Rosetta Life. The audience was made up of people with a definite link to day hospices - a mix of family (20%), friends (7) volunteers (8%) and health professionals (27%) - and others who could not categorise themselves into any of the above (33%) as indicated in Table 4 or Figure1.

Table 4 What is your relationship to the project?

		Number	Percent	Valid Percent	Cumulative Percent
Valid	family member	19	19.8	20.4	20.4
	Friend	7	7.3	7.5	28.0
	Health professional/professional carer	26	27.1	28.0	55.9
	Hospice user	1	1.0	1.1	57.0
	Volunteer	8	8.3	8.6	65.6
	Other	32	33.3	34.4	100.0
	Total	93	96.9	100.0	
Missing	System	3	3.1		
Total		96	100.0		

Figure 1 What is your relationship to the project?



7.2 The Importance of a Professional Venue

There was consensus amongst the audience that the play benefited from being performed in a professional venue (88%) although some felt that it could have been performed in non theatre venues.

Achievement for hospice participants, access to wider audience gives performance more weight and the significance of the topic deserves professional venue

Gives it more standing and gives people the chance to see it who normally wouldn't, not just friends and family

I think the play would have the same strong message anywhere

The audience reported that they would have paid to see the performance (80%) and that their attention was engaged all (79%) or most (21%) of the time.

7.3 The Appropriateness of a Cast of Actors and Hospice Users and Staff

Interestingly, there was a clear endorsement of the collaboration between day hospice users and actors with 96% against actors performing all of the play, and 89% clear that that the users could not have performed without the actors.

It felt important for the hospice users to be able to express their feelings and have a different experience or ways of expressing this.

It was absolutely perfect – actors were spot on, hospice members were both amusing and moving.

Not all hospice users would have had energy to keep that level of performance up

7.4 Effects on the Viewer

Significantly, 76% reported that the play they had just seen, had affected their attitude to end of life and other reported that it reflected their experiences.

I work in the community; I have been a community nurse for past the 22 years this encapsulated so many scenarios

The 'hat's film was very positive and showed the person behind the illnesses, (more of this please)

The play was in part a bit too painful, showing the difficulties of end of life as opposed to positive aspects of the end of life

When asked what they would tell a friend about this performance who had not seen it, there were many responses and this is a selection of them:

That it offered a brief/ small insight into the lives and experiences of those living with a life limiting illness

It was a fascinating transition of patient experiences to the professional stage- extremely moving and very sensitively done.

Insightful, emotional and conveys important information to get people thinking and talking about living life at the end

Uplifting /upsetting. Gives pause for thought! It gives a clear message-enjoy life

Some of the audience had been involved in producing the film which featured day hospice users trying on hats and talking about decisions they had made. One of them wrote:

I would encourage them to attend. It has given me a lot of CONFIDENCE(day hospice user involved in film The Decision)

A member of staff who had seen some of the early stage developmental work at one of the day hospices responded:

Brought together people's experiences. I also saw bits of the development of the play in passing which added another layer to appreciating the play

7.5 Audience Discussion

The performances were followed by an audience discussion with the whole cast – professional actors and users. There was a diversity of response as one would expect. In these discussions, some members of the audience were upset and others were reflecting on the performance rather than the issues raised. One member of the audience asked an actor why she had expressed emotion at the idea of being alone when her spouse would die and herself was tearful. She subsequently told the actor in informal conversation post performance, that seeing the play and this portrayal of anticipatory grief had enabled her to weep about her own loss for the first time.

8. Issues for Further Exploration in Future Work and Partnerships

8.1 Partnership Working with Different Organisations - Contracting and Ways of Working

Rosetta Life has a long track record of partnership working but this programme in the West Midlands demanded working with a range of organisations over short periods – the development of a template approach that was adapted to each setting with a set number of sessions – and this is a difficult task when the organisations and participants are diverse. Owing to the particular context and sensitivity of this type of work the scheduling and the nature of the groups are inherently unpredictable in various ways.

When working with different organisations, hospice managers and organisation leaders may need persuading and reassurance at different levels and different stages that the activities provided by Rosetta Life will benefit their clients in particular ways. Once an organisation is committed, the process of ethical approval, health and safety clearance and risk assessment can take time. During sessions, getting formal consent from participants takes time – especially with people who have different types of impairment.

Delivery of Rosetta Life sessions ideally need to be scheduled at the best time of day, allowing for travel to the venue by people who are probably dependent on others, and the level of energy which participants have. However, there are the needs and routine of the organisation so that it is a matter of what is possible rather than what is ideal. For example, a morning Rosetta Life session is probably more ideal than the slot after lunch yet in some places it was the slot after lunch that is offered such as at the respite home , or Hospice A and B.

Host organisations themselves suffer staff changes and other difficulties which can lead to postponements or uncertainty about the scheduling of a specific project. For example, the key contact staff member at Hospice B was on long term leave which resulted in a delay in starting this project and its viability. Bad weather in February 2009 affected staff as well as clients' attendance. At Hospice B deep-cleaning caused disruption and uncertainty for staff and patients in April. On another occasion an unforeseen competing Valentine's Day offer of a local event for a community group affected the Rosetta Life session. In addition, hospice staff and volunteers may be long-standing, but the groups are transitional and subject to variability according to the current health of those who attend.

Some Rosetta Life projects involve visits by participants to another location such as the Birmingham Repertory Theatre. The logistics of these visits should not be underestimated nor the resourcing required. When the activity involves another major arts organisation, the programme must also accommodate the priorities of that partner.

Partnership working is always complex but in this area all partners need to be aware that commitment and flexibility is necessary owing to the fluidity and complexity of this type of work in these settings.

8.2 Ethical Issues

We would advise that there were some ethical issues that require careful handling in the future work of Rosetta Life. Clearly working with vulnerable people, many living at the end of life or with life limiting conditions, raises ethical issues that those that work with Rosetta Life are grappling with.

Rosetta Life has an approach to requesting consent from participants that is in stages as the projects unfold, so consent is repeatedly sought and people have the opportunity to opt out. As the activities in this work were based within day hospices in the main, on a certain day when individuals regularly visit, the work was on an opt out model rather than an opt in. If you wanted to opt out, you did another activity or moved away from the group, or closed one’s eyes. The requesting of consent for different stages of the work is important and this is likely to need the help of hospice staff if the sessions are delivered by just one Rosetta Life practitioner working solo. Since participants may have irregular attendance owing to ill health, repeated negotiation of consent is necessary.

The rehearsals and audience discussions at the Birmingham Repertory Theatre were filmed without consent being requested. This was sought after the filming rather than before. There needs to be on hand support for individuals who are upset by the issues raised in relation to their own lives at performances.

In the main, this work is carried out ethically and sensitively but vigilance and continued care is needed.

8.3 Staff Back Up and Presence

Working with vulnerable adults living with serious illnesses raises some health and safety issues. One cannot assume that these are fully covered if the workshops are being done in an institutional setting and these are more acute when the work is done outside of an institutional setting. This needs to be in place.

For example at the movement workshops on Sunday afternoons in a respite care home, there were few staff present (students on placements), and moving participants at the beginning and end of the sessions was done by the movement facilitator and the evaluators. When asked staff intervened but they were usually elsewhere. Hospice A staff presence at the Birmingham Repertory rehearsals was important for helping people to access the toilets, and to deal with moments when people felt less well. Similarly at Hospice B, when a user had a small seizure, when working with the facilitator from Rosetta Life, back up was immediately sought and provided by the nurse on duty. The physical comfort and well being of participants in these activities need to be taken into account through careful prior planning.

8.4 Space

Suitable space is not always available at the different venues in hospices or respite care homes. There may be interruptions, other activities, with people coming and going. This is a constraint. In Hospice A and B the open space provided a well defined circle for patients’ chairs, but meant that there were people passing, exiting, coming, crossing at all times It is remarkable that some of the very personal ‘stories’ heard were shared in these circumstances. The space provided at the Residential and Respite Care facility is exemplary in terms of light, space, being closed off and having a calm and uplifting aesthetic.

8.5 Support for Artists Working with Rosetta Life

The work observed by the research team utilises different artists – movement and dance specialists and actors some of whom have experience of working with people living with life limiting illness and others may not. We would consider that an induction session and professional support debriefing meetings are essential so that as Rosetta Life expands and works with more staff in more organisations, the approach and practice remains consistent and reflective supported learning can take place. In some situations, a brief explanation of a specific disease would be needed. This applies to not only those whom we have observed but also to musicians, visual artists and others employed to deliver workshops with people at the end of life.

However adaptable and creative practitioners may be, they are working with vulnerable people. If they are to engage in a project which asks for personal commitment and information, then the facilitator should know as much as possible about their situation, leaving aside their personal medical details.

8.6 The Value of Personal Artistic Work and Group Projects

Rosetta Life work is both individual and group based. There is evidence from the observation sessions that the personal work done with individuals telling stories, writing poems is of immense personal value. This is separate from the group work to produce a film or play. This too has immense meaning and value for the participants and the audiences that see them. The balance between them needs to be maintained and the focus on a group public performance or screening should not eclipse or compromise the personal work, which is more private and less visible.

8.7 Adequate Time for the Development of Partnerships and Preparation and Involvement of Staff

The pressure of delivering to a number of different organisations is a real constraint on the way that Rosetta Life develops partnership working. More time needs to be allowed within the planning and funding for preparatory meetings and debriefing with staff and management at each organisation. This is so that everyone fully understands the nature of the work, the resourcing requirements, can learn from it and feel they participate. This will also allow for fuller briefing to Rosetta Life on the needs and conditions of the users who they will be working with from the staff perspective.

9. Conclusions

The aims of the evaluation as stated were to evaluate the:

- impact on the health and well being of participants in Rosetta Life activities

- understand the process and meaning of participating in these activities for the participants and the artists

- artistic process and merit of these activities
- impact of the performances on the audience

9.1 Impact on Health and Well Being of Participants and Meaning of Participation in Rosetta Life Activities

There is evidence from the case studies through observation and interviews that the majority of participants in the Telling Stories and Seriously Playful work feel that these activities affected their well being and sense of self positively. For those who do engage, the experience would seem to contribute to their health and well being and to facilitate sharing experiences at this stage of living with serious illnesses.

The work of Rosetta Life is extraordinarily original and has meaning for all participants – whether hospice users, health professionals or artists. The work can provide both a living legacy for participants and their families and communities but also can be awareness raising for a wider audience. The partnership working with different organisations is complex, demanding, and necessarily variable depending on the ethos and conditions of the organisations and the personalities of the participants. One size or approach will not fit all and there will be individuals or organisations where the work of Rosetta Life does not flourish or prosper. It is important to have time to give adequate preparation for artists and health professionals working in partnerships with Rosetta Life. Additionally, the workshops are offered as an activity that people have to actively opt out of rather than opt in to. Therefore consent needs to be sensitively handled.

9.2 Artistic Process and Merit of Rosetta Life Activities

There is a conflict between the artistic process aimed at a public performance and developing the work in a totally participant- led manner. Working across different organisations with scarce resource requires a template of a certain number of structured sessions that limits flexibility and creativity. Within these constraints the performance of ‘The Magical Glow of the Co-op’, and the two films ‘Decisions’ and ‘Night and Day’ show skilful artistic endeavour whilst allowing participants a degree of ownership through helping to shape the development work and taking part in the performance. There is scope for screening this work in different settings to stimulate discussion with skilled facilitators.

The fluidity of working with people living with serious illnesses means that the work is challenging and constantly changing. This needs to be made clear to the staff in partnership institutions who may need reassurance concerning the uncertainties of this type of work.

9.3 Impact on Audiences of Performances

There is clear evidence from the survey and comments that the performances had a strong impact on members of the audiences. The audience evaluation is extremely positive and shows keen public engagement immediately after the performances.

Rosetta Life activities in the West Midlands have met some of the aims of the End of Life Strategy of the Department of Health and have contributed to the well being of those living with serious illnesses. Users, staff and artists have found their participation meaningful and the public engagement through performances of plays, and films has been extensive. The work is original and although difficult to plan and deliver owing to its sensitivity and the health of the participants, it has clear value and meaning to those involved

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Appendix 1

Rosetta Life's Previous Programmes of Work

The programmes developed by Rosetta Life and the freelance artistic practitioners engaged by the charity involve people on wards, in day care centres and hospice-at-home teams. Over time, this work has drawn on the expertise of many individual experts and facilitators, some well-known visual and performing artists, and projects have covered a range of art forms including storytelling and drama, film-making, photography, dance and movement, published poetry and songs recorded professionally and publicly distributed. The charity's digital work has grown with the Rosetta Collection, DVDs and other material now available for sale.

One element has been the development of a format in which professional artists have drawn on hospital users' experience to create a performance as with 'The Mariners' (2006-07). In the project which the Warwick team tracked with Hospice A and the Birmingham Repertory Theatre, actors and hospice users performed together in June 2009 in two public performances of 'The Magical Glow of the Co-op'.

Prior to this work with Birmingham Repertory Theatre, partnerships had been established with notable arts organisations (not simply to use the facilities at the venue) e.g. The National Theatre Studio and the Unicorn Theatre, London.

Table 1 lists some of the hospices in which projects have run since 2003-04. This is not an exhaustive list, but gives an idea of the geographic spread of institutions and the range in that some are large metropolitan organisations, while others are small hospices catering for the local community. The 2008 Annual Report observed that 'all hospices remain affiliated to the Rosetta Life network and strong partnership working means that regional and national projects thrive' (p.15).

Table 5 Institutions where Rosetta Life has worked

The Royal Free Hospital, London
Marie Curie Hospice, London
St Christopher's Hospice, London
St Luke's, Basildon
The Northern General Hospital, Sheffield
The Trimar Hospice, Weymouth
St Margaret's Hospice, Taunton
St David's Foundation, Newport
Harris Hospice Care, Orpington St Barnabas Hospice, Worthing
Great Ormond Street Hospital for Children, London
Penrith Day Hospice, Penrith
St Thomas's Hospital, London
Willowbrook Hospice, Preston
Richard House Hospice, London
Highland House, Scotland
Lions Hospice, Gravesend
St Joseph's Hospice, London
St Mary's Hospice, Selly Oak Birmingham
John Taylor Hospice, Erdington, Birmingham
St Giles Hospice, Lichfield
Rainbow of Hope, Sparkbrook, Birmingham
Helen Ley Home, Leamington Spa

It is clear that the charity has worked in innovative ways with people from very different worlds as well as those whose own world has irrevocably narrowed following their diagnosis. It has shown great flexibility and a readiness to ‘go with the flow’, taking risks and making the most of any given situation or group of hospice users. Managing new and on-going projects across the country as well as developing income generating activity puts much pressure on the small group of full-time employees. In 2005-2008 two part-time members of staff were appointed to address a budgetary deficit and to generate income.

Table 2 lists some of the funding agencies which have supported the work of Rosetta Life. The grants they have made have funded specific elements of the charity’s programme. This information is also taken from the Annual Reports made in 2004-2008 to the Charity Commission for England and Wales.

Table 6 Funding Agencies that have supported Rosetta Life

DFES	Capital equipment centres
East England Arts	Artists' fees
Freefall	Video production
Greenwich	Fees for new media tutor in Greenwich centre
King's	Salaries of grant application consultant and creative director
Lambeth	Artists fees for the Life-Long Learning project
Lloyds TSB	Artists' fees
NIACE	Fees for media tutor and training costs
NIACE Outreach	Capital equipment for three outreach centres
NOF	Salaries of production staff, core costs and some administrative costs
Royal Free Hospital	Artists' fees
Southwest Arts	Artists fees and IT equipment for Feasibility Study project
Yorkshire Arts	Artists' fees
St Christopher's	Consultancy fees
St David's Foundation	Artists in residence
Trinity Hospice	Artists in residence
Sheffield	Artists in residence
Culture on line (DCMS)	On line cycle of six songs and four films
Arts Council	Theatrical performances
South West Arts	Tour of the Festival
St Barnabas	Artists in residence
Harris Hospice Care	Artists in residence
NOF	Equipment and fundraising
Penrith	Artists in residence
Paul Hamlyn	Songwriting project for Great Ormond Street Hospital
Help the Hospices	Associate video producer
Awards for All	Theatrical production
Harlington Hospice	Artists in residence
NAHCF	Core funding for management and recruitment of volunteers
Bridge House Estates	Funding for lead artists and for users forums to build the identity of the London Region
Children's Workforce Development Council	Funding for training and developing a workforce for the children's hospice music making project
Mariners	The production and tour of a work of music theatre developed in collaboration with women living with life threatening illnesses
Barclay's Bank	Developing concerts for The Songrooms 2007
Richard House	Funding for participation in The Songrooms
BBC Children in Need	Fees for musicians and part funding for the project managing of The Songrooms

As well as diversifying the art forms through its projects, the charity has engaged in an expanding variety of activities. The web site and virtual opportunities were mentioned above, along with the production of other materials such as DVDs and books of poems (see www.rosettarequiem.org). It has run Festivals of the Arts in Palliative Care (2004, 2005, with a tour in the South West in 2005-06). Work with children who are seriously ill has been established. Training sessions have been provided for professional artists and for NHS staff in hospitals and hospices. Presentations at national conferences have disseminated the work of the charity. Rosetta Life has begun to develop international links and conducted in-house research with the Living Body Alliance on the potential for movement and dance in palliative care. This resulted in a new focus on movement work with people who have neurodegenerative conditions.

In 2009 Rosetta Life moved its Head Office to Oxfordshire, coinciding with a major new programme of work for the Pan-Birmingham Palliative Care Network. Subsequently this was taken over by the Birmingham North and East Network.

Appendix 2

Overview of Work in Arts and Health and Well Being Programmes

There has been a growing interest in the role of the Arts in relation to Health and Well Being. A review by Arts Council England (2002) had a section on visual arts and health (p.35-52) that included projects reviewed by Prevista. These projects are summarised below and indicate that there is emerging evidence that visual arts impact on patients' well being where these projects were evaluated.

Vital Arts, the arts charity for Barts and The London NHS Trust, commissioned artists to enhance the hospital environment, programmed live music and performances, curated two exhibition spaces and managed the Trust's collection of 1,200 works of art. The project received generous funding from charitable donations, had a sympathetic design team, a supportive Trust and strong patient and staff interest. The project aimed to create a positive and comforting environment for patients and their families, provide distraction, relief from anxiety and intimate spaces for time out, realise patients' aspirations for the centre not to look or feel like a hospital . It was felt that the project achieved the highest standards in delivering a welcoming, comfortable and reassuring physical environment for patients, their families and staff, who are often experiencing high levels of stress and engaged clinicians, patients, architects, artists and curators in the consultation process.

The Chelsea and Westminster Hospital Arts Programme involved the presence of major, large-scale commissioned artworks throughout the airy, bright modern building and these had a spectacular impact. Hospital Arts, which commissions and programmes work, is led by consultant doctors who ardently believe in the arts as part of the healing process. In 1999, Hospital Arts initiated research into the effects of the Hospital Arts programme.

The Aims included:

- introducing the best contemporary art and multicultural live performances into the daily routine of the hospital
- assessing patient, staff and visitor attitudes to the visual and performing arts in a healthcare setting
- assessing the impact on staff
- measuring the effect of arts in health on clinical outcomes

The evaluation revealed that there had been an impact on patients, staff and visitors.

- chemotherapy patients who were able to view rotating art exhibitions during recovery showed reductions of 20% in anxiety levels and 34% in depression, compared with control groups
- 75% of patients, staff and visitors reported increased enjoyment and mood enhancement, reduced stress levels and a welcome distraction from immediate worries
- two-thirds considered the role of the arts in the healing process was important
- arts in health programmes played a part in staff decisions about where they chose to work and whether they planned to stay in post

The research findings were widely disseminated in professional journals and in The Healing Environment, published by the Royal College of Physicians. The evidence of the benefits of integrating the arts into hospital healthcare on patient satisfaction and outcomes and on staff morale have influenced policy makers, hospital managers and clinicians.

The East Sussex Hospital Trust's Arts in Healthcare programme was in 2002 one of the NHS's longest-running and most integrated arts programmes. Over the previous four years, the Arts in Healthcare programme had included site-specific artists' commissions, exhibitions, residencies, workshops and commissions re-using architectural ornament from redundant hospitals.

Visual arts projects included: artists working with occupational therapy teams and with patients whose illness or disability limited their access to participating in the arts; weekly art sessions with stroke patients and their visitors, focusing on handling materials and tools, using both hands, refining motor skills and practising good hand eye coordination to speed recovery and alleviate the mental and physical effects of stroke; and a pain management course of art sessions with patients experiencing long-term pain, to help them move towards a self-managed approach. The aims included:

- integrating the arts into healthcare services for the therapeutic benefit of patients and staff and enjoyment of the local community
- improving recovery and quality of life for patients
- extending a sense of value, well-being and social interaction for staff

The evaluated impacts included a range of effects. These were that:

- there was a reduced intake of drugs by some patients
- it demonstrated that arts activity can help stroke patients rebuild confidence and regain mental and physical function and coordination
- it benefited patients, who are able to concentrate on something other than their illness, and to share goals and learn new skills
- it provided professional and vocational development opportunities for staff
- it enabled staff, who value this, to reflect critically upon their work practice by engaging with challenging contemporary art dealing with complex issues
- it received consistent support from Trust staff and management

Lime, in Wythenshaw, an award-winning team, ran arts projects in healthcare settings across Greater Manchester. Its work was based on the belief that the arts can play a key role in individuals' and communities' physical, mental and spiritual health. Artists in residence worked with staff and patients in the Cystic Fibrosis Unit of the Acute Hospital on a project entitled Me Myself I. Commissioned artwork, photography and creative writing by staff and patients were used to explore identity, legacy and remembrance.

Manchester has the highest levels of mild to moderate mental health problems in the UK. Because of the association between mental ill-health and economic and social deprivation, Lime's three-year Pathways community programme used participatory arts to explore creative solutions to mental ill-health in some of the most deprived areas of Wythenshawe. Research was undertaken by Manchester Metropolitan University.

The aims included:

- to take a joint-agency approach to enable people to be creative, thrive and prosper
- integrate arts, health and social agendas to make a sustainable impact on healthcare culture
- make consultation and participation central to all projects
- seek imaginative alternatives to traditional healthcare practice

Amongst the impacts it was concluded that in the Cystic Fibrosis Unit, Me Myself I helped banish the feeling of boredom and isolation that can result from prolonged time in hospital.

Art in health and well-being at the end of life: assessing excellence, risk-taking and innovation

The history of arts interventions as part of a range of alternative approaches to health care include art therapy, use of art to improve the hospital environment and as part of treatment and recuperation (Windsor 2005). Engagement with the arts can be grouped under access, attendance and participation (Windsor 2005). Although illness limited attendance and access, Windsor (2005) found it did not seem to diminish participating in creative activities:

> ‘Limiting longstanding illness was clearly associated with attendance and media access to the arts. Taking each of the various means of engagement in the arts separately, people with a limiting longstanding illness were less likely to:
>
> - attend both performing and non-performing arts or culture
> - participate in sociable or physically demanding dance activities
> - listen to arts programmes on the radio
>
> Those with any type of longstanding illness (limiting or non-limiting) were, however, more likely to participate in creative activities than people with no longstanding illness.’
>
> (Windsor 2005 p86)

This is at the heart of the activities of Rosetta Life: the premise that people living at the end of life or with longstanding illness will have their well-being enhanced by participation in creative artistic activities.

This evaluation is designed largely as a qualitative investigation aimed to focus on the ways in which the projects initiated by Rosetta Life affect the quality of life of participants. This aligns well with the priorities of the recent report *Supporting Excellence in the Arts. From Measurement to Judgement* (McMaster 2008). While its author does not specifically address arts initiatives in the health sector, he does offer pointers pertinent to this study:

> The best definition of excellence I have heard is that excellence in culture occurs when an experience affects and changes an individual. An excellence cultural experience goes to the root of living.
>
> (McMaster, 2008, p9)

The Rosetta Life projects are being developed for specialised situations with people living at the end of life. Any project which sets precedents like this moves into uncharted territory. But this too is part of the excellence which artistic activities should seek:

> For something to be excellent it has to be relevant, and for it to be relevant it has to be continually reinterpreted and refined for and by its audience. Risks have to be taken, innovation must be central to the process.
>
> (McMaster, 2008, p10)

And assessing the value of such endeavours requires more than just head-counting:

> It is necessary therefore to move from a system based on measurement to one based on judgement, and one that in making judgements in excellence, innovation and risk-taking, doesn't end up discouraging all three.
>
> (McMaster, 2008, p21)

Two strategies which are advocated are self-assessment and peer review. This evaluation sits alongside those strategies by creating opportunities for reflection, de-briefing and on-going assessment by all parties. The variety of methods used meant that through individual interviews and group discussions, through oral and visual evidence, we could build a multi-layered picture which allowed for analysis of a complex programme so that the experience gained could be shared with others.

Appendix 3

Topic Guides and Consent Forms

A Getting involved

How did you hear about this project?
Why did you decide to get involved?
What did you hope the project would offer you?
What did you personally hope to achieve?

B What happened

What actually happened in the project?
In what ways did it meet your expectations?
Were there any problems? How were these overcome?
Did some things happen which you found surprising?

C Effects/Impact

Have you noticed any particular effects on yourself?
Have you noticed any effects on other people?
Has it contributed to your well being? If so, how?

D Suggestions

If you were running this project or a similar one, would you make any changes? If so, what? Why?

What were the high spots/successes which you like to be replicated?

What will you take away from being involved in the Rosetta life project?

Artist and Health Professional information and consent form:

We are contacting you as someone who is taking part in workshops and projects organised by Rosetta Life in the West Midlands. Our research team has been asked to evaluate what it means to people who are involved with these activities and we would like to hear your views.

We will be holding a workshop that will give you and other artists time to reflect on what you expected, what it has been like and how it has impacted on your well being. It is important to evaluate these activities, so that they can be improved or further developed in the future.

We will record the workshop discussion but all information would be confidential and anonymous and the recording would be destroyed after it is transcribed. Should you wish to withdraw from the workshop or interview, you can of course do so.

We also would like to interview a few artists individually. If you are willing to be interviewed and/or take part in this evaluation workshop in …………. on ………….. from…………, you can give your consent on the other side of the page.

I agree to attend this evaluation workshop	Yes	No
I agree to the recording of this workshop	Yes	No
I agree to be interviewed individually	Yes	No
I agree to material possibly being used for publication or presentation in an anonymised format	Yes	No
I understand that I can withdraw from the workshop for or the interview at any time	Yes	No

Name Signed Date

Participant Consent Form

We are contacting you as someone who is taking part in workshops and projects organised by Rosetta Life in the West Midlands. Our research team from the University of Warwick has been asked to evaluate what it means to people who are involved with these activities and we would like to hear your views and reflections.

We will be holding a workshop that will give you and others time to reflect on what you expected, what it has been like and how it has impacted on your well being. It is important to evaluate these activities, so that they can be improved or further developed in the future.

We will record the workshop discussion but all information would be confidential and anonymous and the recording would be destroyed after it is transcribed. You can withdraw from the workshop at any time.

We also would like to interview a few participants individually. If you are willing to be interviewed could you please agree to this possibility on the next page.

If you are willing to take part in this evaluation workshop in ……………………… on ………….. from…………., you can give your consent below.

I agree to attend this evaluation workshop	Yes	No
I agree to the recording of this workshop	Yes	No
I agree to be interviewed individually	Yes	No
I agree to material being used for presentation or publication in an anonymised format	Yes	No
I understand that I can withdraw from the workshop or the interview at any time	Yes	No

Name Signed Date

Project Location

Appendix 4

Audience Feedback Form for Magical Glow of the Co-Op - Rosetta Life Production at the Birmingham Rep.

Dear Audience Member

We would like to know what you feel about this performance tonight.

The Strategic Health Authority, West Midlands has asked for an evaluation of the work of Rosetta Life in the West Midlands. The project of which the play is a part is funded by the NHS to mark the culmination of the Living Well to the End of Life Campaign.

Would you be so kind as to fill in the questions below as fully as you can and hand this sheet to a member of the evaluation team who will be positioned outside to collect your responses as you leave. There are a number of pens on the table outside.

Thank you for taking the time to fill this in.

Best wishes

Gillian Hundt

Gillian Hundt on behalf of:
Sheila Galloway
Claudette Bryanston
Maria Stuttaford

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Audience Feedback Form – June 2009

1. Did you find that the play held your attention all of the time or most of the time?

   All ☐ Most ☐ Some ☐ None ☐

2. Would you have preferred it to have been acted by an entirely professional cast?

   Yes ☐ No ☐

   If yes, why?

3. Do you think that all the roles should have been played by the hospice users?

   Yes ☐ No ☐

   If yes, why?

4. Would you have paid a normal ticket price (average £12) to come and see this play?

   Yes ☐ No ☐

5. Do you think that it was important that this play was performed in a professional theatre venue?

   Yes ☐ No ☐

   If so why?

6. Do you consider yourself a theatre goer?

   Yes ☐ No ☐

7. What is your relationship to the project?

   Family member ☐ Professional carer ☐
   Friend ☐ Hospice user ☐
   Health professional ☐ Volunteer ☐
   Other ☐

8. Has this play affected your attitude towards people living well at the end of life?

   Yes ☐ No ☐

9. Have you or anyone you know been involved in a Rosetta Life project?

Yes ☐ No ☐

If so, what was it?

10. Would you be happy to be contacted by one of our evaluators in the near future if so please can you leave your name, phone number or email?

Name:

Phone:

Email:

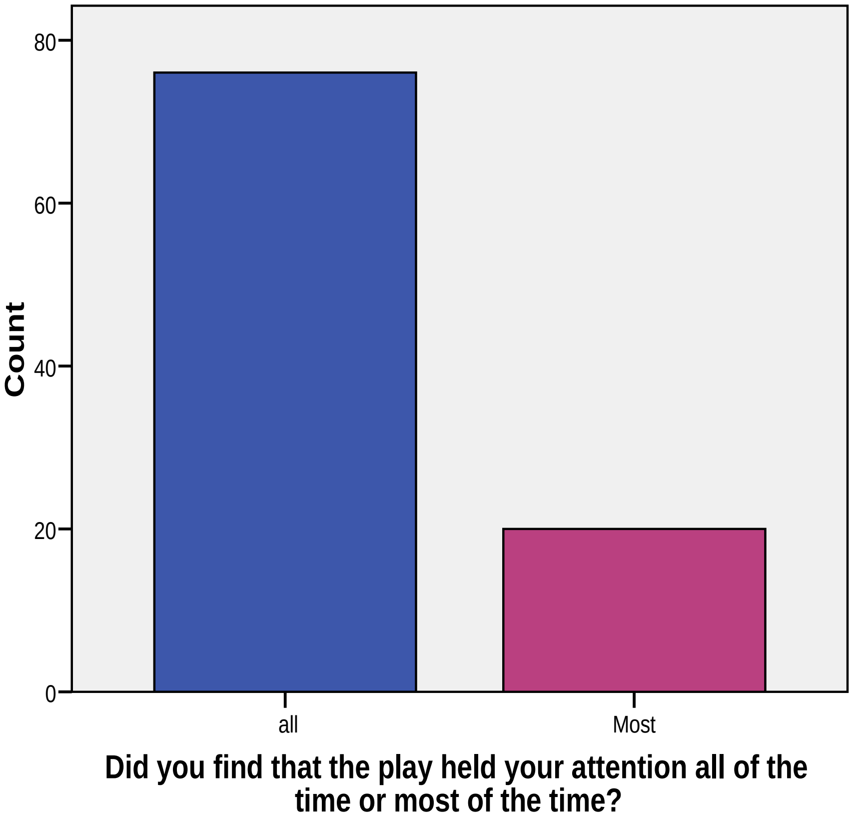
11. If you were telling a friend about this performance, what would you say?

Audience evaluation of performances at the Birmingham Repertory Theatre

‘The Magical Glow of the Co-op’ - June 2009

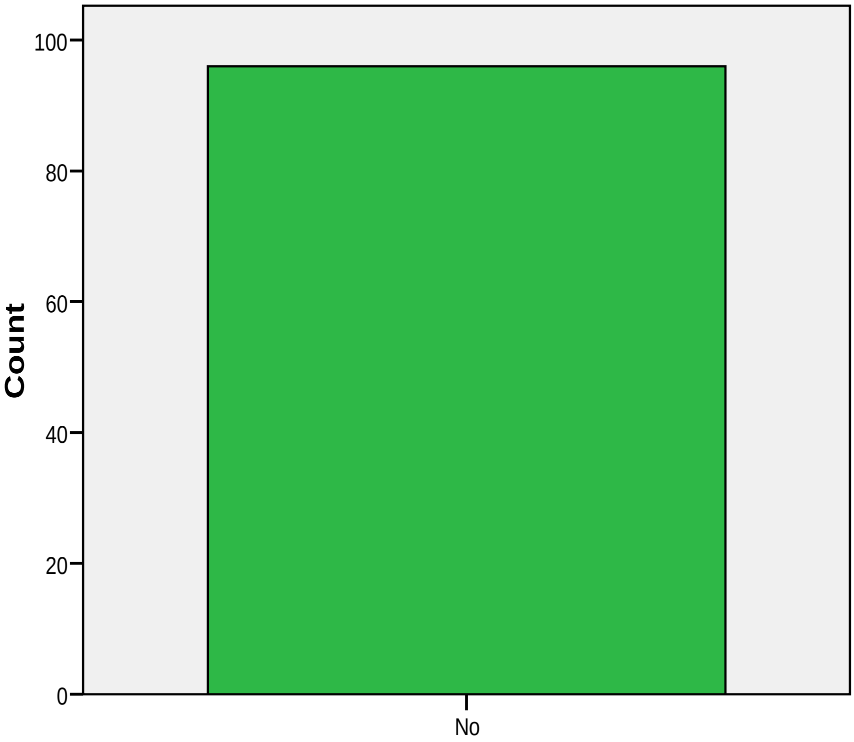
Did you find that the play held your attention all the time or most of the time?

		Freq	Percent	Valid Percent	Cumulative Percent
Valid	All	76	79.2	79.2	79.2
	Most	20	20.8	20.8	100.0
	Total	96	100.0	100.0	



Would you have preferred it to have been acted by an entirely professional cast?

		Freq	Percent	Valid Percent	Cumulative Percent
Valid	No	96	100.0	100.0	100.0



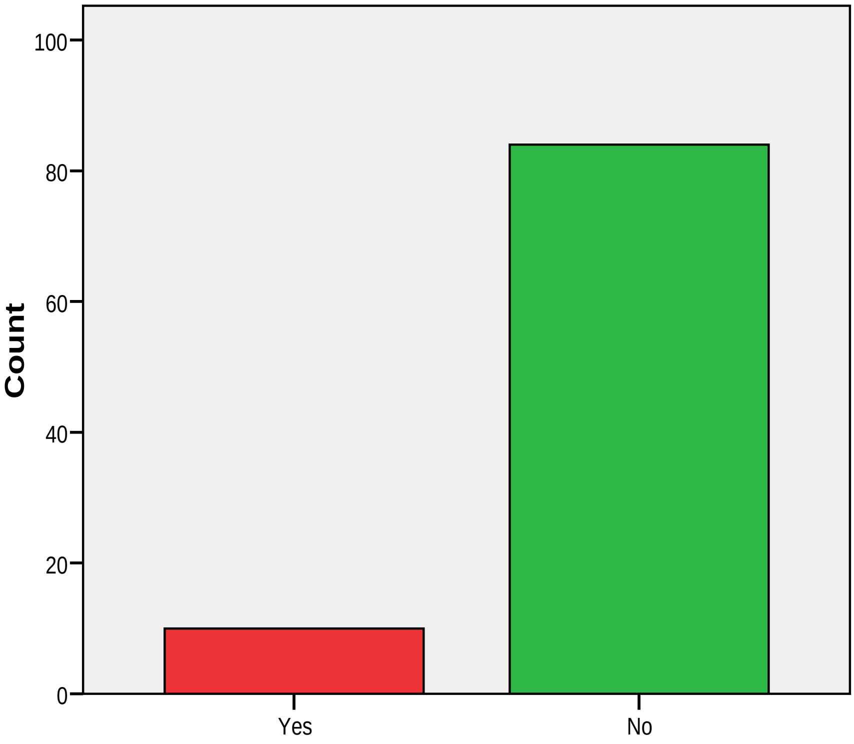
Would you have preferred it to have been acted by an entirely professional cast?

Q 2. Would you have preferred it to have been acted by an entirely professional cast?

52	All can join in
65	It was very real
72	It felt important for the hospice users to be able to express their feelings and have a different experience or way of expressing this
79	It was absolutely perfect actors were spot on, hospice members both amusing and moving

Do you think that all the roles should have been played by the hospice users?

		Freq	Percent	Valid Percent	Cumulative Percent
Valid	Yes	10	10.4	10.6	10.6
	No	84	87.5	89.4	100.0
	Total	94	97.9	100.0	
Missing	System	2	2.1		
Total		96	100.0		



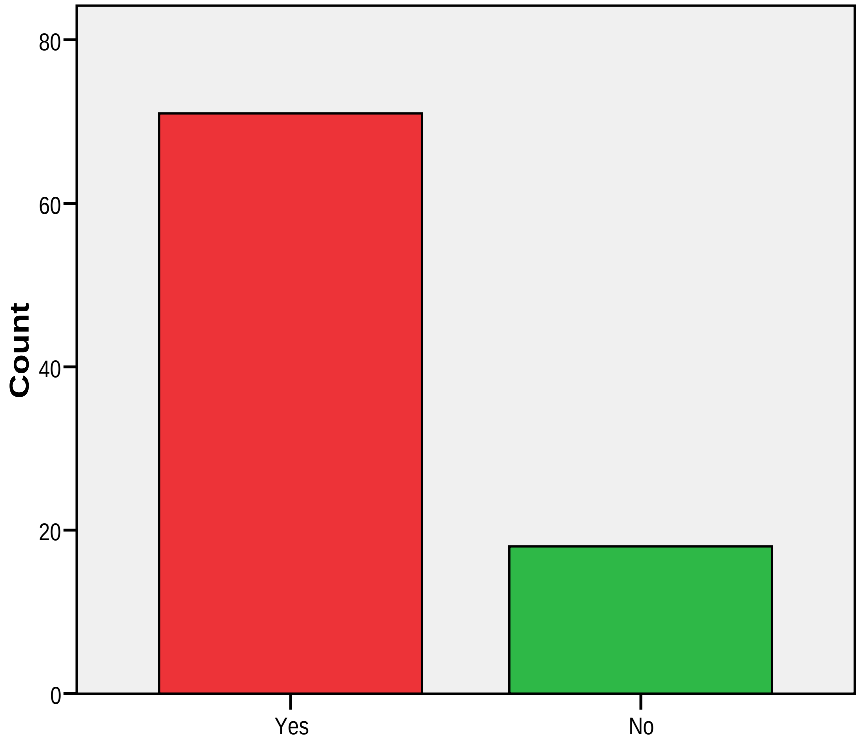
Do you think that all roles should have been played by the hospice users?

Q 3. Do you think that the roles should have been played by hospice users?

2	Idealistically but impractical
9	I thought it was a good mix between professionals and hospice users
11	Realistic
32	Because palliative care issues involves all members of a community we all have think from all sides
37	It would have been great to have more involvement by hospice users, yes but not necessarily all
43	They would be acting their life story
44	Brings insight to part professional actors was not be able to
64	The play shows that just because your at a hospice life isn’t over
72	I think I would have liked to see more involvement from users but useful to have support from professionals possibly
73	Could be taken into the community
75	Made it a real event-a night to remember for the folks from this hospice
76	Because a topic like this needs to be treated professionally and given the respect and showcase it deserves
78	More people attend /mix of people potential for greater audience and with increased platform and spread of awareness
79	Not all hospice users would have had energy to keep that level of performance up

Would you have paid normal ticket price (average £12) to come and see the play?

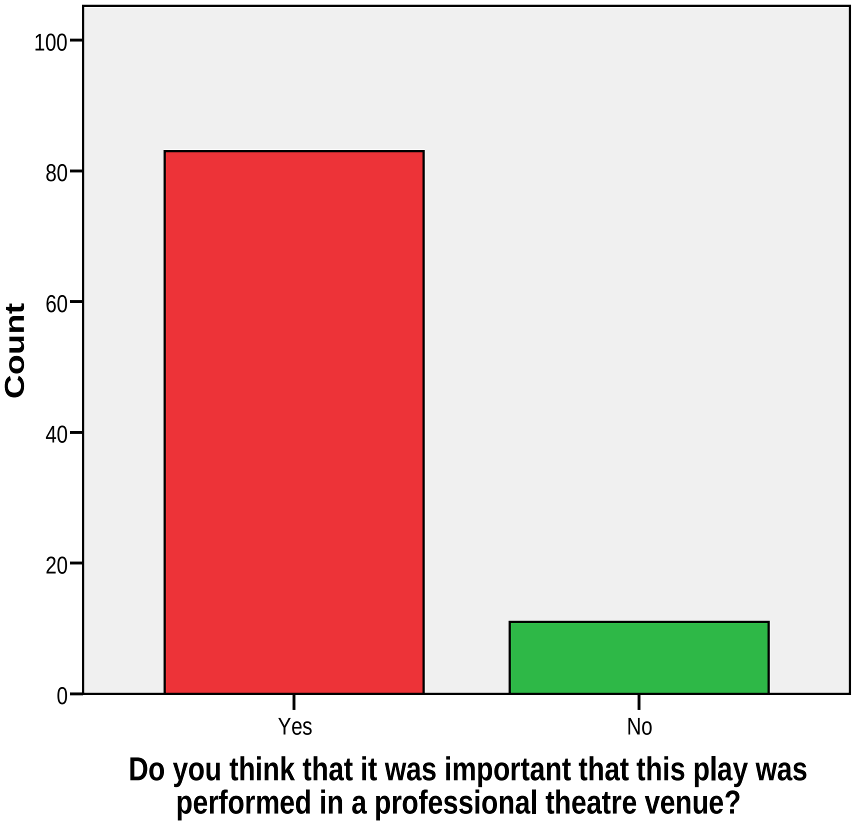
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	71	74.0	79.8	79.8
	No	18	18.8	20.2	100.0
	Total	89	92.7	100.0	
Missing	System	7	7.3		
Total		96	100.0		



Would you have paid normal ticket price (average £12) to come and see this play?

Do you think that it was important that this play was performed in a professional theatre venue?

		Freq	Percent	Valid Percent	Cumulative Percent
Valid	Yes	83	86.5	88.3	88.3
	No	11	11.5	11.7	100.0
	Total	94	97.9	100.0	
Missing	System	2	2.1		
Total		96	100.0		



Q 5. Do you think it was important that this play was performed in a professional theatre venue?

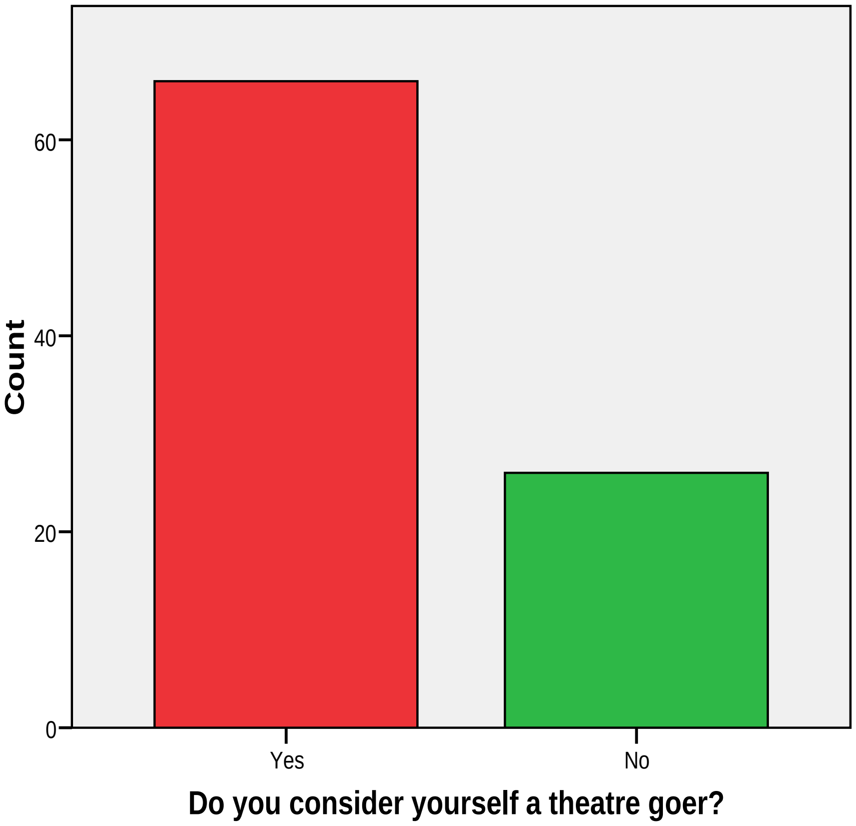
1	Sense of accession, enables the rep to reach out, hospice patients to experience real drama acting in a theatre
2	
4	To give a sense of grandeur and importance to the event. Make the participant and audience feel more involved in something special
5	Because it was more enjoyable for those taking part and make the message get across to those attending more we really made an effort to behave
6	It heighted the importance of what being acted out and gave the cast from the hospice worth
8	Gives credence and value to process + more comfortable for audience

9	I think it would be good to make the performance available to wider audience
10	I think it should be made it available to wider audience
12	Gave the hospice participants a chance to feel a real achievement something to aim for
13	I think the venue acoustic and lighting added to the production
17	Gives greater value
18	Facilitators were excellent
19	Made message more affective how choice so important
20	Gives value to the message of the experiences of the hospice users
21	Ensure that it reaches a wider audience
22	Professional presentation and prestige
23	I think the environment of a theatre venue added to the power of the messages behind the play
24	But it helps
26	So that theatre goers can experience all types of theatre and human experiences
27	I feel it added to the atmosphere but ..work in other venues
28	Because it made it a ‘professional’ play performed in a professional place and the rep has a great reputation so its support was good
30	It emphasize the importance of such a performance, promotes that something so real is as important as the make believe plays etc
31	Good in schools too
33	It deserved a professional venue
34	Give right tone and supported professional quality
35	I think the play would have the same strong message anywhere
36	It added structure
38	To draw people in To ground it in real world To uplift/validate the ‘patient’ stories and their To show it off to best advantage
39	Makes it more powerful
40	I think this gave it the credibility the professionalism and importance that it deserved
41	It gave a sense of occasion and the lightening and sound added to the performance
43	Sets the scene
44	Achievement for hospice participants access to wider audience gives performance more weight and significance of topic deserves professional venue
46	Because it had an important message which is wider than just a local concern
48	Performing in a professional theatre gives the piece added gravity in the eyes of the public at least, a professional settings also affirms the affects of participants
49	Because otherwise it would not have been sufficiently valued
50	In the mainstream, not on the periphery
52	For health and safety reasons
53	Because this gives credence to the purpose and message from the hospice mates and provides all the cost with a better living
54	To get the professional feel of it
55	Makes patients feel special
56	Gives it more standing and gives people the chance to see it who normally wouldn’t, not just friends and family

57	It gave it more authority and more importance
58	Bringing to attention
59	I believe this gave the play/performance a central venue that it deserved
62	Gives it credibility and value
63	To give proper recognition to the value of this project
64	By being shown some where professional it gets the people in to watch
65	Gave it extra value
66	It helps the audience concentrate their minds because of the ...... of such a venue
67	It has as much (if not more) validity as any other play
68	Generally, people notice or look for professional theatres and what they are doing so this type of performance would get more notice
70	It shows respect for participatory theatre and the approach in general and the service users comfortable for audience and hopefully also for hospice users
71	Because it an important theme plus needs to be valued
79	Because community/participatory art deserves as much limelight is as valid and important a art form as any other (some might say more so plus gives participants genuine theatre experience
80	For affect and enjoyment
81	But it would have also been just as powerful in community setting
82	Because it doesn’t hide people illnesses
85	Take more seriously
86	Because people think of it more important
87	Because it allowed more people to come and watch
88	Gives authority less like amateur drama mates
89	I felt that this play could had been played anywhere
90	Death should be taken more seriously than it is. Most people do not even consider death until it happens to a loved one of theirs
91	It normalise life, which is what the play was about
92	Adds is the impact of the message
93	Anywhere will do
95	Sense of accomplishment for hospice users many of them valued the experience of being in a theatre, something didn’t think i’ll do
96	Slows respect for the performance

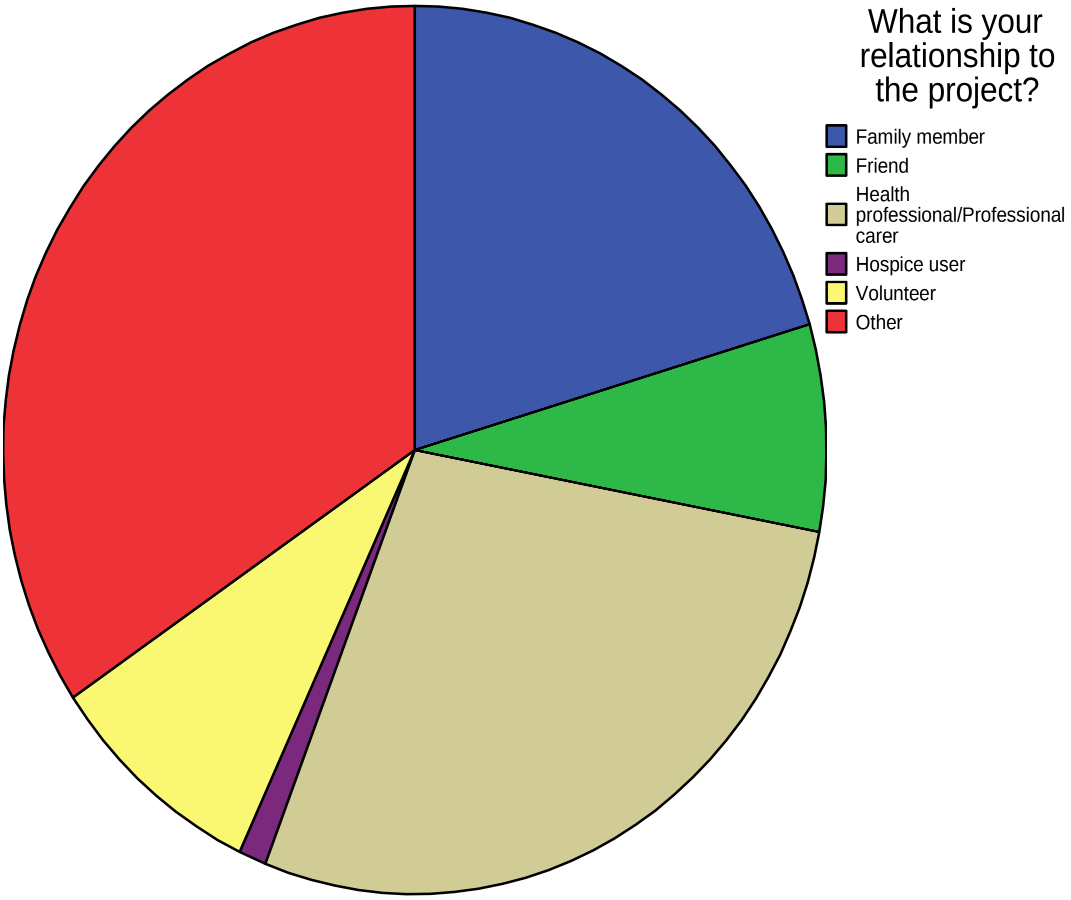
Do you consider yourself a theatre goer?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	66	68.8	71.7	71.7
	No	26	27.1	28.3	100.0
	Total	92	95.8	100.0	
Missing	System	4	4.2		
Total		96	100.0		



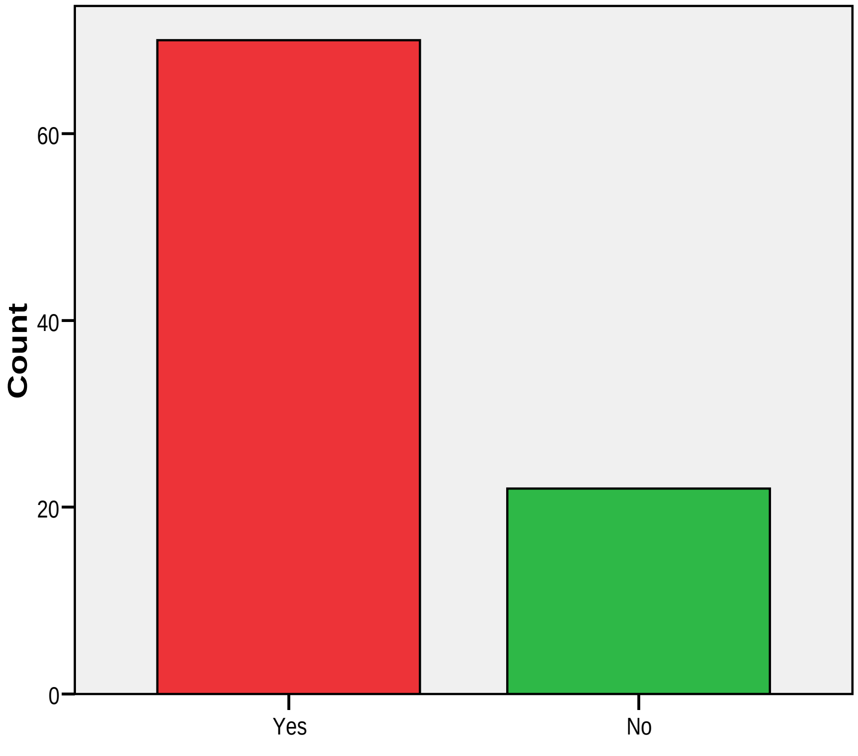
What is your relationship to the project?

		Freq	Percent	Valid Percent	Cumulative Percent
Valid	Family member	19	19.8	20.4	20.4
	Friend	7	7.3	7.5	28.0
	Health professional /professional carer	26	27.1	28.0	55.9
	Hospice user	1	1.0	1.1	57.0
	Volunteer	8	8.3	8.6	65.6
	Other	32	33.3	34.4	100.0
	Total	93	96.9	100.0	
Missing	System	3	3.1		
Total		96	100.0		



Has this play affected your attitude towards people living well at the end of life?

		Freq	Percent	Valid Percent	Cumulative Percent
Valid	Yes	70	72.9	76.1	76.1
	No	22	22.9	23.9	100.0
	Total	92	95.8	100.0	
Missing	System	4	4.2		
Total		96	100.0		



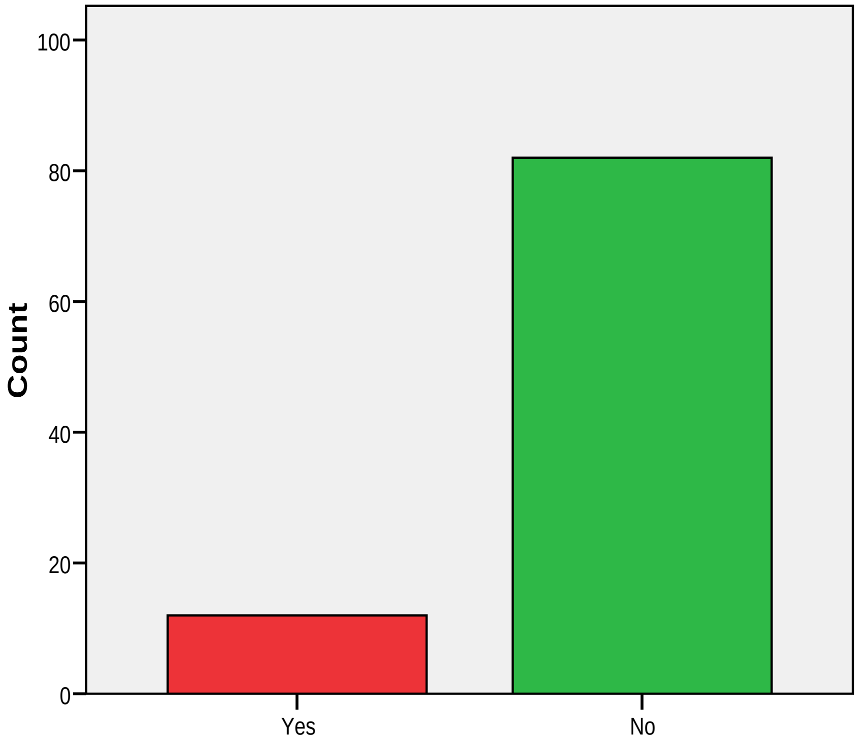
Has this play affected your attitude towards people living well at the end of life?

Q8. Has this play affected your attitude towards people living well at the end of life?

2	The professional tendency to over protect
23	I have a professional role in the end of life
27	I work in the community, I have been a community nurse for the past 22 years, this encapsulated so many scenarios.
38	In fact I had hoped that it would challenge the myths more than it did especially the actual play at St Mary
44	That ‘hat’ film was very positive and showed the person behind the illness (more of this please)
	The play was in part a bit too painful, showing the difficulties of the end of life as opposed to positive aspects of end of life
90	I have always thought that death should be with dignity
95	Everything offers an insight to me, you always see things from variety of perspectives-different people , different personalities, different opinion of life
96	Not fundamentally, but I had thought about it a lot before

Have you been involved in a Rosetta life project?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	12	12.5	12.8	12.8
	No	82	85.4	87.2	100.0
	Total	94	97.9	100.0	
Missing	System	2	2.1		
Total		96	100.0		



Have you been involved in a Rosetta life project?

Q11. If you were telling a friend about this performance, what would you say?

1	An eye opener- a new dimension on living (dying)
2	You missed something valuable
3	Fantastic
4	That it was inspiring, heartfelt and emotive
5	What an eye opener it was and how brave the individuals were and how they continue to enjoy their lives regardless of what they are facing with their illness This should be shown to young people in education .....they waste their lives
6	It highlighted the important of what was being acted out and gave the cast from the hospice self worth
7	Moving
8	Brilliant go see it, keep funding
9	It is an interesting insight in to a very difficult subject
10	It was thought provoking
11	Eye opening
12	Consider the peoples' wishes. Also how family are affected. Very worthwhile project
13	Powerful, poignant ,thought provoking
16	Many characters meet
17	Interesting important work moving great idea
19	Brilliant
20	Very good
21	That it gives accurate reflection on the experience at end of life.
22	Don't bring a noisy baby
23	Very powerful, clearly could see the work and effort that had gone into its preparation
25	It was well acted
26	It's a production based on real experiences and should be seen at least once
27	Powerful production, I think it would not appeal to everyone. But in a society where death is taboo we need this openness
28	Because it made it a 'professional' play performed in a professional place and rep has a great reputation so its support was good
29	Very emotional and real life events that do happen and how important family life is and making the right choice for yourself
30	It portrayed the reality of living with and caring for a person with limiting illness
31	Sharp, moving, ''tells it like it is'', but it is not sloppy
32	I would encourage them to attend stress the community one member from St Giles film, it has given me a lot of CONFIDENCE
33	Brilliant
34	Engaging, challenging, moving
35	Insightful and touching. Put things in perspective Loved the cells-add something extra

36	Brilliant
37	Would have been good to integrate film into performance/thought provoking and insightful script/prof cast did really well with questions
38	That it offered a brief/ small insight into the lives and experiences of those living with a life limiting illness.
39	Brought together people experiences. I also saw bits of the development of the play in passing which added another layer to appreciating the play. Have you recovered any of the development work?
40	It was a fascinating transition of patient experiences to the professional stage-extremely moving and very sensitively done.
41	An insightful and thought provoking play well worth watching
42	Very interesting and stress on the family decisions
44	Stay for the discussion session because that helps a lot in understanding the whole concept and background of the play. Also brings in once again the people behind the illness and some laughter
45	Learn and reflect on stage of life one avoids
46	A humorous sensitive play with an important message
47	Insightful, emotional and conveys important information to get people thinking and talking about living life at the end
48	Insufficient space here. In short remarkable piece of work.
49	Go.......!! It’s not maudlin
50	It encapsulates the ‘crunch’ issues around terminal illness from the perspective of the patient the family and the carers
51	Excellent , help general public realise live each day Important for hospice patient too feel part of the general public
52	Very good
53	This was a very painful message regards cancer and its effects on different works of life
54	That it was good and helpful
55	Would not recommend it, thought it was very inappropriate for the audience to be photographed and filmed throughout without being asked, informed or warned. Felt the hospice users were being promoted too much in the Q&A. Liked the interaction of hospice users during performance
56	Better than I expected , parts it were moving, it’s better than some professional plays I’ve seen
57	It was well worth coming to and certainly ‘good for thought’ I was most impressed
59	Amazing and had a great impact
61	Well worth spending an evening getting under the skin of family with terminal illness
63	Very moving, insightful and thought provoking
64	I would tell them to come and see and a play that is very emotional and open about a subject that is pushed under the carpet to much
65	Very powerful medium to develop thinking
66	See it, if you ever have a chance and listen to what is said
68	Wonderful, I would say it is a very worthwhile production to see, am so glad I went
69	Listen and learn, a good story about hope and determination, very good

	drama-educational too
70	Feeling safe is essential to happiness, communities vulnerability, which is too often silenced so it can stimulate read talk about feelings
73	Very informative
74	Well acted and thoughtful production very moving at times
75	Eye opening and very ,very moving
76	Uplifting /upsetting. Gives pause for thought! It gives a clear message-enjoy life.
77	It’s a warm and friendly way to learn about hospices and carers
79	Moving , important and beautiful
79	Touching and life affirming
81	Very insightful, powerful and moving
82	It was very touching and real
83	Good true honest tale all about real life something that is important to us all
84	Real life portrayed very well
86	Interesting , real encouraging
87	Very interesting , sad it made me think about things that are close to me
88	Interesting to see how people feel about end of life and hear about their lives
89	Real and to the point
90	It should be shown or performed in schools to try to stop young wasting their youth
91	It is a look at the importance of living a normal life even though you have life limiting illness
92	Amazing , insightful
93	Very involving and true life in portraying the tension involved in a family. Good to see the carers roles brought to the front
94	It will help you understand illness and dying from different perspective
95	Very insightful
96	It carried great authenticity