

Seed Funded Projects Self-evaluation Report : *How are you feeling? A stroke survivors' poetry project.*

Length: Up to 3 sides of A4, with additional income and expenditure sheet. Please include direct quotes where applicable in sections 3, 4 and 6.

1. Brief Description of Project

This is a writing project, which focuses on the emotions evoked by having, and recovering from, a stroke, in order to shape positive rehabilitative narratives with stroke survivors. Working in partnership with Kate Tym, a St.Leonards based performance poet, testimonials were gathered from stroke survivors which then formed the basis for a collection of poems. These poems were then 'fed back' to the stroke clubs through a performance and also used to provide another form of input to nursing staff and those in training.

2. Project Progress

- What did the project partners and stakeholders plan to do?

We planned to run a project involving three stroke clubs: Hove, Woodingdean and Hastings. The project would take the form of information gathering (involving staff and student volunteers) – whereby testimonials were gathered through conversation with the organisers and attendees. These testimonials were then to be used as the basis for a collection of poetry written by Kate. The poems were to be fed back to the stroke clubs, and to nursing and other health care students at the university to demonstrate the experience of stroke and its effects, and the power of arts-based healthcare education and learning.

- What did they actually do?

We actually fulfilled the project as outlined above. The partners gave us time and opportunity to speak with the stroke club members and their family members and friends also attending the clubs.

- How were volunteers involved?

Volunteers were mainly involved in the information gathering process. This meant attending stroke clubs on several occasions and engaging in conversation with the organisers and members attending. During this process volunteers took notes and listened very carefully to the experiences that were being outlined. They then wrote up the notes and highlighted particular phrases or thoughts that they found pertinent or poignant. The volunteers also had the opportunity to attend the 'performance' element of the project. One volunteer also attended the staff meeting of the School of Nursing and Midwifery to report on how he had found the experience of volunteering and what he had got from the experience.

- Please describe the evolution of the project and reasons for any changes to the plan/timeline

The project actually ran pretty much to schedule and stuck to the projected course as outlined in our initial proposal. The only aspect we have not been able to fulfil within the timeline is a published pamphlet. We have had to investigate other sources of funding, which is time consuming, as we want to produce a pamphlet with fairly professional production values. We also want to include a CD with recordings of the poems on it, as many stroke survivors have difficulty reading, this will enable them to share in the poetry too. This is important as the pamphlet can continue to be circulated and used as a resource long after the project has been completed.

3. Partnership working

- Which partners and stakeholders were involved?

Our partners were Hove, Woodingdean and Hastings Stroke Clubs.

Kate Tym was the creative practitioner co-ordinating the project.

University of Brighton academic staff: Debbie Hatfield, Dr Alec Grant, Dr Kay Aranda

Nursing student volunteers – Guy Chetwynd-Appleton, Deb Simmonds, Grahame Gillespie, Michelle Bunce, Ermelinda Da Costa. Sarah Rodgers, a sports science student also took an interest in the project and attended one of the performance sessions.

- How did the partnership work?

Kate was the instigator of this project and did the initial groundwork, contacting the clubs and encouraging their involvement. After the initial 'setting up' of the project Kate and the university volunteers had four points of contact with each club. Firstly, an introductory meeting where Kate went along explained the nature and aims of the project and explained the process of taking part and how the stroke clubs would be involved. The second and third visits were by Kate and volunteers in an information gathering capacity. And the fourth was a performance and feedback session. At the same time Kate and the three academic staff members had around six progress meetings to keep the project moving and on-track.

- What knowledge was exchanged and developed?

A huge amount of information was obtained from stroke survivors on how having a stroke had impacted on their lives. All of the volunteers commented that they had found out things they would never have found out in their role as a nursing student in practice, because the questions they were asking were very different.

Debbie Simmonds, a student from the February 2009 cohort said:

'Thanks so much for allowing us to take part in the poetry project. I feel that I grew from the experiences that were shared with us by these wonderful and amazing gentlemen.'

Guy Chetwynd-Appleton said:

'I would not have seen this in the hospital'

Those in the stroke clubs also felt they gained some insight into their own condition as it was reflected back to them in a different way. This 'knowledge' has also been disseminated through 'guest lecturing' by Kate, and once the pamphlet is published will continue to circulate more widely. Kate also gained an insight into the world of academia which is very different to the creative environment she usually inhabits!

- What did On Our Doorsteps contribute? What other support would have been useful?

It created the opportunity to take the idea forward. There was a lot of enthusiasm but limited scope due to monetary constraints. This project rapidly allowed access to the stroke survivor's world and gave an additional voice to the stroke clubs as service users.

4. Neighbourliness

In what ways did the partnership promote an exchange between university and community that connects to themes and ideas of neighbourliness as set out in your original application? What were some of the challenges to this?

Involving the stroke clubs immediately introduced the element of 'neighbourliness' and working within the community. This partnership was very noticeable for the student and staff volunteers who had perhaps not ventured 'out' into the community to a very large degree prior to this project. Equally, the stroke clubs were very welcoming and seemed delighted to have the university involved and interested in what they do. The main difficulty we had was getting student volunteers to commit to their expression of involvement. This was to some extent due to the restrictions of when the clubs met, although there may have been some apathy because of assignment deadlines.

5. Outputs

What did the project produce? (eg conference papers, articles, book, film, new courses/modules, community outputs such as training sessions and questionnaires)

A pamphlet is in the pipeline (ie designed and ready to print once funding established). It is hoped that this pamphlet can also be distributed in association with the Stroke Association. This pathway is being investigated at the moment.

Increased service user involvement in the curriculum. Kate has spoken to postregistration nurses on the new stroke module as a visiting lecturer. It is hoped there will be more opportunity with other students in the future. The academic staff has seen the potential due to Kate's performance at the general staff meeting. Some of Kate's poems plus photographs from the performances have been added to the School's service user and carer web pages. An article has also appeared in the student newsletter.

Articles – an article about the project has already been published in the stroke newsletter for the SE Region, produced by the Stroke Association. One will be published in the national Stroke Association Magazine – Stroke News – in the New Year.

6. Outcomes

What impact do you think the project had on:

- the community organisation/s and stakeholders

The stroke clubs all gave very positive feedback and valued the opportunity to be involved with CUPP at the university. Hove stroke club has representatives attending the National Stroke Conference who will further publicise this project.

- the university

Interdisciplinary working : members of staff have worked with others from the community with whom they have not worked before, through the themes of community engagement, service user involvement and the role of arts in healthcare. Working with a creative practitioner has been very different for academic staff as demonstrated by Kate's presentation at the general staff meeting. Feedback was very positive and other members of staff expressed an interest in running similar projects, e.g. positive experiences of pregnancy and childbirth.

New course module for the newly validated pre-registration nursing degree – arts in healthcare – the appropriate content of which will be shared with existing modules and courses. Kate Tym will hopefully continue to contribute as a visiting lecturer.

Research: Kate Tym and Dr Alec Grant hope to work together again in the future on an arts in healthcare/research project. Alec has considered the theoretical background of this future project as follows:

In line with the broad focus of concern of the healthcare professions, and those involved in healthcare on a voluntary basis or as a carer, art speaks to humanity and to human suffering, recovery, development and loss. Art can represent and provide testimony to all of these experiences in many forms, including the important contribution of narratives (eg Frank 1995; Grant et al. 2011; Sandelowski 1994), in prose or poetic form. In related terms,

engagement with art can be therapeutic, healing, and facilitative of self-development for users of healthcare across the lifespan (eg Eakin 2003; Frank 1995; Grant et al.2011; McLean 2010;; Staricoff 2004; Stickley et al. 2007).

However, it has been argued that individual narratives of trauma and pain can be silenced or erased by cultural master narratives (Davoine and Gaudilliere 2004; Gordon 1997) In this context, the significance and contribution of art in healthcare is always in danger of being eclipsed by the dominant, positivist-informed biomedical model of healthcare research in the developed world. While the contribution of biomedical research is clear, its exclusivity serves to marginalise and even silence much of the knowledge of human suffering, adaptation and recovery held by 'experts by experience' (Grant 2011). Clearly, such silenced voices, as artistic and narrative product, have much to offer healthcare practitioners and others about the experience of illness, adaptation and recovery.

Epistemologically, when engaging with the knowledge produced in the poems from the stroke survivors project, all of the stakeholders in this project – patients, relatives, volunteers, healthcare staff and students, academic staff, and the wider civic community – will engage with a different kind of knowledge. All stakeholders have been more or less conditioned into ways of knowing which are determined by, and derive from, the assumptions and principles of positivist science. The poems from this project, about or around the stroke experience, will help readers and listeners begin to 'see', 'know' and 'feel' the stroke phenomenon differently (Rumbold et al. 2008). This will include through and with voice, bodies, images and collaborations (Liamputtong and Rumbold 2008). Such embodied, experiential and relational forms of knowing in turn facilitate increased sensitivity and attunement between individuals in new forms of intersubjective knowing; knowing with and responding to each other in new, more empathic, ways (Rumbold et al. 2008; Seekey and Reason 2008).

References:

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- Dissemination: performance and pamphlets which will continue to be used as a resource and disseminated through several different arenas, i.e. Stroke Association. Kate is also a regular speaker to WI groups, U3A, NHS retirement fellowship etc and can talk about this

project and promote the pamphlet. It is also intended that this project will be written up for appropriate peer reviewed journals.

7. Longer term knowledge exchange work

Please describe what your partnership plans to do next.

- How will the project and/or relationships develop at the end of this seed funding?
 - New course content on existing modules with Kate contributing as a visiting lecturer. See above.
 - Project performances are also planned for the District General Hospital, Eastbourne and the Conquest Hospital, Hastings to develop a rapport with the 'Stroke Team'.
 - Possible further links with the Stroke Association to promote this project.
 - Pamphlet as a long-term legacy of the work and continuing resource.
 - Further publications are planned for nursing and health/social science journals.
- How will the role of volunteers be developed to support future work?

The experience has helped explore how students can be supported in community engagement type projects. Debbie Hatfield will be leading a CUPP type module for the new Nursing curriculum in 2013 which focuses on contributions to community organisations.

8. Statement of Income and Expenditure

Please explain any discrepancies between the budget in the project plan and actual income and expenditure.

Our budget plan and actual expenditure were quite accurately met. It would have been good to have more money for the pamphlet production as we are now trying to find other sources of income to fund this. Also, the budget did not take into account work done retrospectively. So the number of meetings and amount of organising and admin that took place to get the proposal to a point of readiness to apply for the funding all was done voluntarily.

9. Quantitative evaluation

Please give an estimation of:

- The number of people involved in the partnership

1 creative practitioner

3 academic staff

6 students

Around 100 stroke club organizers, volunteers and members

- The number of people involved in events/workshops you have run

200

- The numbers of people who have benefitted from the activities you have undertaken

So far, around 200: everyone who has taken part has had the benefit of an insight into the emotional landscape of having a stroke. With continued visiting lecturing and performances being planned at DGH and the Conquest this number will rise. And once the pamphlet is published and promoted this will reach more people again.

- The numbers of hours the partners have worked on the project and please indicate by how much this number was more or less than you initially planned for.

The number of hours was fairly accurately estimated.

Where more hours were spent on the project than planned, please indicate how this time was paid for, or whether it was voluntary

APPENDIX

Suggested Impact Indicators

1. University

1.1. Staff

- training of tutors
- staff promotion
- networking within university
- interdisciplinary connections and connections across the administrative divide

1.2. Teaching

- influence on teaching methods
- new course content on existing modules
- development work on new modules/courses
- validation of new modules/courses

1.3. Research

- RAE submission/facilitation
- influence on colleagues' research base

1.4. Student Learning

- student opportunities and experience in community practice
- student dissertations
- enrolment on new modules/courses

1.5. Dissemination

- conferences
- papers
- books
- email influence
- invitations to disseminate (eg as keynotes speakers)

2. Community

2.1. Staff

- experience teaching on university modules
- continuing professional development

- skills development support
- increased job satisfaction
- increased staff/volunteer competence, credibility, employability & promotion

2.2. Service users

- benefits to local economy and quality of life for individuals
- improved access to services
- developed understanding of user need

2.3. Organisation

- savings to service providers
- organisational change
- increased funding
- increased ability to articulate and promote work

3. Joint

- Joint funding submissions
- Influencing local and national practices, strategies and policies
- Development of new services
- Ongoing relationships with project partners
- Community of practice development