Marcia Ley and Mark Mulqueen 2014 Room for You Arts in Health Paper (poster) THE ART OF GOOD HEALTH AND WELLBEING 6th international Arts and Heath Conference .National Gallery of Victoria , Melbourne, Australia

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Room for You – Arts in Health Abstract Submission, July 2014

The impact of cancer does not end after treatment. The 'Health and Well Being Survey' by Macmillan Cancer Support in 2008 found that cancer survivors reported poorer health and well-being than the general population. The health and well-being profile of the cancer survivor population is comparable to the population of people with a chronic condition such as diabetes or arthritis. Much of this can be attributed to the consequences of cancer treatment.

In May 2009, the National Cancer Survivorship Initiative (NCSI) undertook a mapping exercise to identify the key aspects of the health and well-being, care and support needs and experiences of people living with and beyond cancer. This mapping exercise suggests that some of the key issues for survivors include:

- psychosocial issues including anxiety, depression,
- isolation and negative impacts on self-identity or self-image,

Room for You is an arts in health charity in the North East of England. It was set up in 2001 to relieve the tension and apprehension often felt by patients (and their families) as they wait for cancer treatment or following treatment.

Room for You's unique and innovative feature is the way it pairs artists with counsellor facilitators, to ensure a high degree of sensitivity towards patients and carers and enable them to participate in the art work in a supported way.

Room for You offers a safe, accepting and transforming space within a hospital, hospice or community healthcare setting where patients and carers can engage in arts activities and/or conversation. The artwork is used as a vehicle for what we provide, which may be listening time as much as creative opportunity.

The aim is to meet the patient or carer where they are in their unique journey in a respectful, caring and supportive way.

The Room for You model demonstrates how arts in health services can alleviate stress and anxiety and assist in the development of ‘creative’ coping strategies. This paper will consider how the model can be adapted for a range of health care contexts.

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Aug 2014

Room for You Arts in Health Paper

Melbourne Presentation

Room for You’s Charitable Objectives:

The main objectives of the charitable company are to ‘protect and preserve the physical and mental health and to assist the rehabilitation of the general public, patients, former patients and carers.

For: the advancement of health or saving of lives.
Who: the general public.
How: provide services.

Room for You's Statement of Purpose is:

> To provide emotional support (through creativity and listening) to people living with life limiting, long term conditions.

Brief History

Room for You has been in existence for 12 years as an unincorporated project and for the last two years as a charitable company. We are based in Newcastle upon Tyne in the North East of England. Our core service is based in the three main hospital's providing Cancer Treatment in the North East; at the Northern Centre for Cancer Care in Newcastle; at the City Hospital in Sunderland and at the Queen Elizabeth Hospital in Gateshead.

We have also established four 'Arts for Wellbeing' workshops in identified strategic 'cold spots' for therapeutic provision in the North East. Specifically these community based workshops are in, Wallsend on the banks of the River Tyne and in Blyth, Alnwick and Hexham, which are all in the beautiful county of Northumberland.

How we work

We believe that the unique feature in our way of working has been to pair a professional artist with a qualified counsellor who acts as a facilitator, bringing a high degree of sensitivity to the experience and feelings of those attending treatment so that participation is accessible in whichever way they choose, whether that is to engage with the arts activity or simply to talk to the facilitator, artist and others.

Some time and space to review their experience of how their condition is impacting on their life with a non-medical ally is valued by the patient and carer alike.

Quote from the Sister in a Cancer Unit

> ‘The artists and counsellors from Room for You can provide time with the patients that our staff cannot always guarantee. This is both beneficial for the patients who get involved and for staff who are able to leave patients knowing that they are engaged in something that they are enjoying. It is anticipated that we (the hospital) will see more positive patient feedback as a result of this service.’

How do we make people ‘feel’ better?

We begin by offering people the opportunity to join in an art activity, either individually, or as part of a group. We always attempt to engage them in a purposeful conversation, in which we listen and think about the patient or carers needs as well as trying to discover ways in which they are already being creative, whether they recognise it or not. Patients may adamantly state "I'm not artistic" but will happily discuss the artwork on their walls at home, activities they have done with their children or other hobbies and interests, such as gardening or fishing. We have the view that everyone is capable of being creative and will seek to find a way for this to be expressed in whatever setting we are working in.

Our counsellors frame conversations around people's interests, assisting them to state psychological strengths, identify positive aspects in their life and in respect to the challenges that they face, help to develop coping strategies with them. This doesn’t happen in one conversation and we may regularly see the same people throughout their treatment period, allowing us to build relationships and provide a consistent point of contact.

The artists offer a range of artistic activities that are specifically designed to be as accessible and inclusive as possible, enabling everyone whatever their experience or ability to achieve something that they are proud of and are happy to share with their family and friends.

This is not about dumbing down, but rather it is about planning for success to build confidence and self-esteem in the participant. The artworks produced too must be of a high enough quality to stand up in their own right!

Another aspect of our work is the normalisation of an ‘alien environment’- the hospital. We do this by helping to make connections between people to facilitate peer support. This can be about connecting anxious strangers in a waiting area but it can also be about enabling dialogue between family members.

On occasion our counsellors have been able to help strained relationships by talking separately with both patients and their carers, establishing a neutral contact who can act as an advocate, helping to regain trust and confidence.

Staff at each location have stated that the atmosphere is totally different when we are working in their venue.

Changing the physical environment of an existing space is another way we alter what may otherwise be a sterile medical space, introducing, colour, creativity and interest.

In July, we started working in a 10 bed residential hospice, (St Bede’s Palliative Care Unit). Since then we have installed an eleven foot wall hanging, plus three other large artworks; designed a soft furnishing colour scheme, set up a ‘memory tree’ in the staff room and each of the individual rooms has a bespoke name plate based on the castles of Northumberland.

A day in the life of an Artist

The best way to describe how ‘Room for You’ works is to, describe a typical day in one of the health care settings in which we work.

Northern Centre for Cancer Care (NCCC), waiting area in the Radiotherapy department, Freeman hospital.

The NCCC waiting area feels very corporate and office like. It has black chairs and grey walls but it overlooks a courtyard with a garden and if the weather permits the first thing we will do is go out into the courtyard and put up kites and flags, giving colour to the outside space all year long.

Radiotherapy treatment lasts just a few minutes a day, but the waiting can vary from 40 minutes to several hours, depending on how many staff are

working and if all the machines are operating. A course of treatment lasts on average six weeks, which means a patient needs to attend the NCCC every day, Monday to Friday for this full period. This effectively put ordinary life on hold for the length of treatment. Naturally patients and their carers are often anxious and fearful and this makes the Radiotherapy waiting area a very hard place to be.

This is the context for which I will design an activity for the day. I set up an Art activity table in a position where as many people can see it as possible. Activities include watercolour painting, lantern making, collage, printing, drawing, silk painting to name just a few. If I'm silk painting I will have a large ladder frame placed on the table.

It's my aim to make the table look as interesting, inviting and as non-medical as possible. It has decorative tablecloth, lots of colour, paints and other art materials. It looks deliberately out of place!

As the table is en-route to the coffee bar a lot of people walk past, look at what's going on at the table, and often stop. I will chat to them about the activity and invite them to come and have a go. Sometimes they might say yes, but more often they will decline at this point. However the connection is made and they will come over to the table each week for a chat. After a few weeks they may sit down and have a go at something.

At the same time as I am working at the table, Mary the Counsellor/ facilitator will work her way around the waiting area asking if they would like to know what I'm doing. She invites people to come over and have a look and maybe a go. Some people jump at the opportunity to do something and come over and get involved. Others welcome opportunity to have a conversation with someone who is a trained listener and will talk to Mary without ever coming to the table. Mary doesn't counsel, but she does use those skills to support the people she talks to and gives then space to talk about whatever they choose. This teamwork is one of the strengths of 'Room for You', it enables us to effectively reach many more people than either of us could as individuals. It's a really effective working method.

On a busy day I will work with 40 or more people directly. But the impact of the art table is much wider; it reaches just about everybody waiting. Once people have initially come over to visit the table they will come every week of their treatment and as they build up trust and confidence they often talk about their cancer journey while they are working with me. Others will want to talk about other things; families, jobs, their creative interests. Some enjoy the art activity so much that they look forward to seeing me, coming over and joining in. It becomes one of their coping mechanisms.

The full effect of 'Room for You' on the waiting area is transforming, it lifts the whole atmosphere of the area and at the very least it gives patients and carers something to watch while waiting. For others the opportunity to offload some of their fears on someone outside their family and friends is very valuable, while for other people it can be a space to escape to and do something that is both distracting, enjoyable and creative.

As an Artist working in this environment I feel humbled by the people that I meet and it is my aim to support them by encouraging them to engage in the creative process and providing a good listening ear.

<u>The Act of Making</u>

'Being engaged with your hands gives your head a break!'

We define the way we use art as follows –not as arts therapists but we employ art in a therapeutic manner- using the therapeutic qualities inherent in creative play. This means that the artistic activity is a vehicle for emotional support and not for a specific diagnostic purpose.

We are aware that the boundaries between our approach and the discipline of 'Arts Therapy' can appear blurred. However we do not explicitly offer the opportunity for self-examination or reflection through images. In our work artists direct projects, which means the role of the image is different and as mentioned, no one is purposefully exploring it for meaning. Clients therefore benefit from being creative; through the colour and textures of art materials, therapeutic nature of processes, gaining a sense of achievement from these

activities and boosting their self-esteem by doing what they didn't believe was possible.

There are also the social and support benefits of this type of group work. This obviously affects mood, cognitive processes and psychological state; even if perhaps in a low key, or seemingly low impact way. This is not to say it is insignificant.

We also have good communication and working relationships with the wider staff in each setting and are aware of safety protocols and the facilities in each venue.

An example of how we work: -

Recently some of our colleagues have been working with a woman in her thirties who comes in once a week for her chemotherapy. They were having a conversation about how adults don't get much opportunity to play and she told us how significant the first time we had worked together had been for her. Spending an hour or so working on a small silk painting had made her realise how she hadn't relaxed for a very long time.

She said:

> 'It made a real difference to me; I now make an effort to spend an hour or two every week making something so that I can relax!'

The 'Arts for Well Being' workshops give greater scope for developing a participants artistic skills and confidence as it takes place with a regular group over a period of six weeks. It is also an effective vehicle for developing peer support in a safe atmosphere.

<u>How do we 'measure' impact?</u>

We use our 'Well-Being Wheel' [FIG 1], which is similar to the 'Outcome Star' methodology, to measure the distance travelled by the people engaged with our work in the community through our 'Arts for Well-Being' workshops. The Arts for Well-Being workshops take place over six weeks in an inspiring venue

if one can be found. (In a community centre right on the beach in Blyth; Alnwick Gardens in the grounds of Alnwick Castle).

Macmillan Cancer Support refers patients and carers to us. We usually register 12-14 people to each workshop with the expectation that 8 – 10 will be able to attend in any given week.

With the ‘Well Being Wheel’ we try to capture on two occasions, the first and last workshop sessions, how the participants are feeling about: their self – confidence, whether they feel they are achieving, how they are coping, whether they feel supported, are feeling creative, feeling anxious, feeling relaxed, and if they are able to concentrate.

From the monitoring of our 'Arts for Well Being' workshops we know that there has been a significant improvement for our patients across all these categories. For example there has been up to a 40% improvement in the coping skills of the participants sampled. Up to 67% have said that they feel more creative and up to 71% report that they are less anxious following our interventions. However every cohort is different in terms of age, energy and their health (which of course affects ability to attend) so the results can vary. The average percentage improvement across all categories from our workshops over the last ten months is 25%.

There are challenges in gathering meaningful data from a client group in a hospital context so there we use staff observation and experience to record each ‘one to one’ encounter with a patient or carer. We record basic information about the patient and as you can imagine we hear a range of issues and challenges in these one to one engagements.

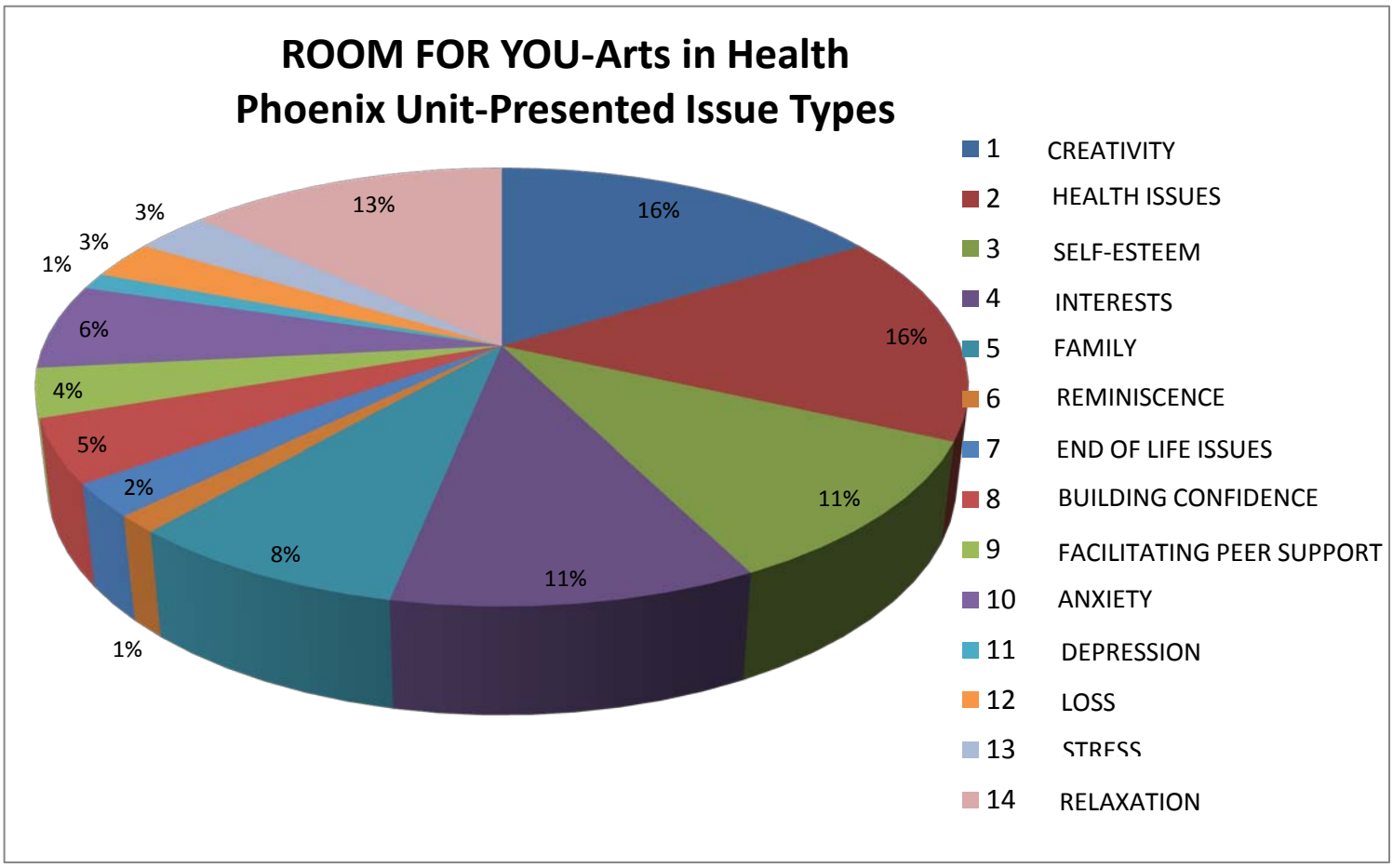
We have organised these issues for recording purposes into fourteen categories.

These categories are: Creativity, Health, Self –Esteem, Interests, Family, Reminiscence, End of Life, Building Confidence, Peer Support, Anxiety, Depression, Loss, Stress and Relaxation.

The purpose of these evaluation tools is to monitor our effectiveness in helping people in terms their independence, their ability to cope with their condition and the impact it has on their family and social lives.

We are also able to build up an emotional landscape over time, for our stakeholders, the NHS Trusts on how their patients are feeling and coping whilst undergoing treatment.

(City Hospital Sunderland Pie Chart showing presented issues over a three month period)



On average we are able to directly engage with 550 people per month across our hospital and community based services in seven sites. This means that we engage with over 6,000 people in each year.

'Talking is good!'

The success of the model we have developed over the years in different healthcare settings is based on the partnering of an artist and counsellor to offer emotional support to patients and their families.

The key to effective working is the building of relationships. Of course our main objective is to try to build relationships with patients and their companions each time we meet, wherever they may be in their treatment cycle.
We hope that what we can offer therapeutically grows and improves as trust develops. At the same time, we recognise that building good relationships with staff is equally important and we hope that with time staff understand and value how patients and carers can benefit from supportive listening and creative opportunities. Healthcare staffs' overt acceptance of the project gives patients confidence, and integrating us into the whole process/team allows patients to be more receptive to our offer.
Where this happens we are part of an integrated service to cancer patients and their carers in the North East of England.

We have seen how the combination of art and counselling works well in hospital and community settings.
Talking initially about the creative piece of the day is always an effective informal introduction to who we are and what we do. Patients and family members who get involved are thrilled to take part and, when appropriate are so pleased to take away their very own piece of 'art'.
They all say it helps!

Demographic Information

The incidence of cancer is higher in the North East than in the rest of the country. The national DSR (Directly [Age] Standardised Rate) rate is 412.8 the DSR for the North East is higher at 440.1 Source: Male Incidence 2004-2006, NCIN/APHO/UKACR from Cancer e-Atlas 2010

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Appendix
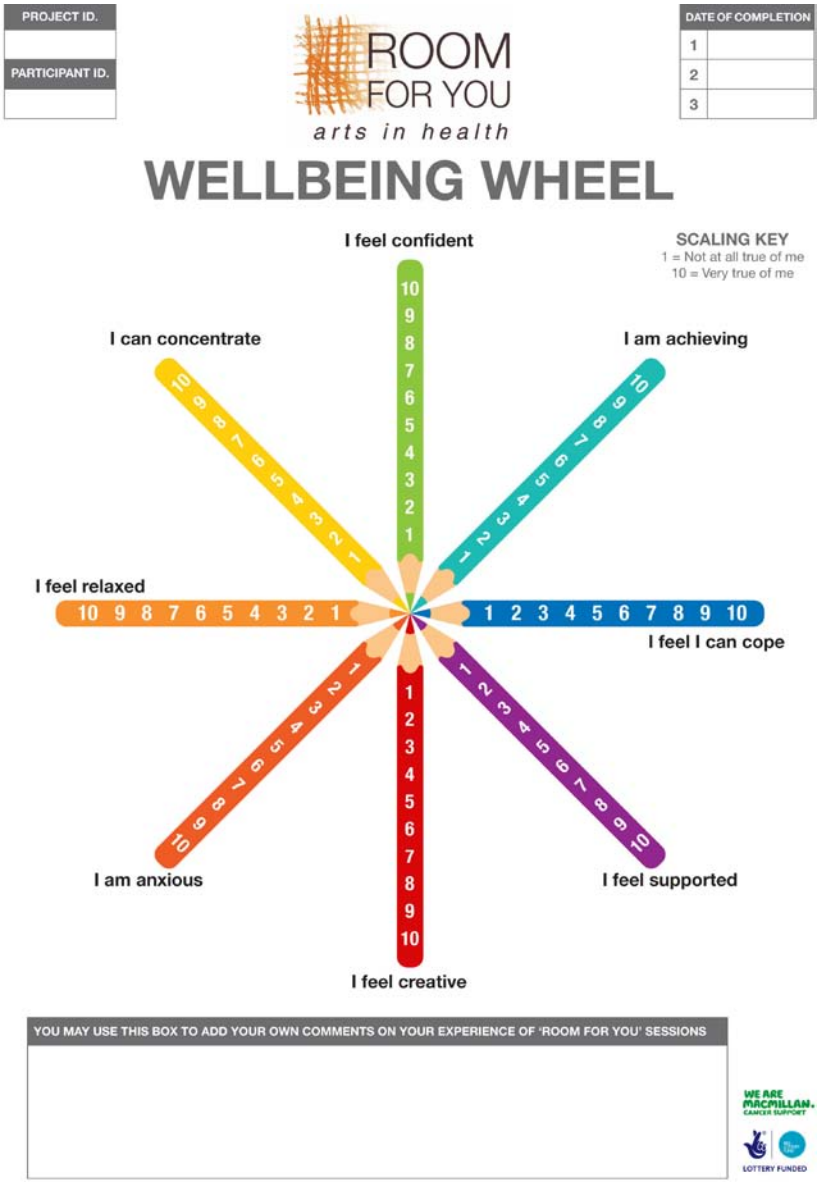
Figure 1