MSc in Lifelong Learning

FLEXIBLE CURRICULUM FOR ACCESS AND PROGRESSION

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Engaging carers: discovering the passion and the poetry through an exploration of flexibility, facilitation and collaboration

Name:	Pip Hardy
Student number:	13939503
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Contents

Care*, n. Solicitude, anxiety; occasion for these; serious attention, heed, caution, pains; charge, protection, etc.*

Care*, v.i. Feel concern or interest* for or about*; provide food, attendance, etc.,* for *(children, invalids, etc); (w.neg. expressed or implied) feel regard, deference, affection,* for*, be concerned whether etc)*

Concise Oxford Dictionary (1964)

'What carers do should be properly recognised, and properly supported - and the Government should play its part. Carers should be able to take pride in what they do. And in turn, we should take pride in carers. I am determined to see that they do - and that we all do.'

Tony Blair (2001) Introduction to National Strategy for Carers

'The central theory [of curriculum] is simple. Human life, however varied, consists in the performance of specific activities. Education that prepares for life is one that prepares definitely and adequately for these specific activities. However numerous and diverse they may be for any social class they can be discovered. This requires only that one go out into the world of affairs and discover the particulars of which their affairs consist. These will show the abilities, attitudes, habits, appreciations and forms of knowledge that men need. These will be the objectives of the curriculum. They will be numerous, definite and particularized. The curriculum will then be that series of experiences which children and youth must have by way of obtaining those objectives.

Franklin Bobbit, 1918

*'****Engaging****: 1. Bind by contract or promise (esp. of marriage). 2. Hire (servant); bespeak (seats, cab, etc.). 3. Pledge one self (to do) guarantee, promise. 4. Induce; attract, charm, Fasten (pillar) into wall; interlock (thing). 6. Hold fast (attention) employ busily. 7. Embark. 8. Bring (troops) into conflict; enter into conflict with.*

Concise Oxford Dictionary (1964)

There will be dying,
There will be crying, but there is no need to go into that
The poems will flow from the heart unbidden
And the hidden source is the watchful heart

Derek Mahon

1 Meeting client and community needs in the context of socio-economic change and lifelong learning strategies

> *'Users and their carers should have choice, voice and control over what happens to them at each step in their care.'*
>
> NHS Cancer Plan

Some 5.7 million carers provide the vast majority of health and community care in the United Kingdom. Varying reports estimate the value of the work done by carers as somewhere between £34 billion and £57 billion per year – this is roughly equivalent to the entire UK budget for health (the NHS budget in 2003/4 was £56 billion).

The National Strategy for Carers outlines the Government's intention to give carers greater prominence, both in terms of acknowledging the enormous contribution they make to the health service and by providing greater support for those who care. This strategy is also underpinned by the need to improve concordance with drug treatment

One of the best ways of empowering carers is, first of all to acknowledge their existence and, secondly, to acknowledge their considerable knowledge of the people for whom they care and range of conditions affecting 'their' patients. In other words, health professionals need to listen to and respect carers' experience and expertise, and carers need to have the confidence to speak up so that they can be heard.

The National Clinical Governance Support Team (NCGST) has an ongoing commitment to improving the experience of patients and carers. The CGST's Patient Experience Team works to improve patients' experiences of health care, supporting more effective means of engaging patients and communities in their local services. As part of a broader programme aimed at improving communication between doctors and patients, it is essential to involve carers, particularly for those people whose voices may not be heard because of stroke, mental illness, dementia, extreme youth or extreme old age, speech difficulties or other problems.

The Heart of Care is a project that has been set up by NCGST with the intention of producing a series of publications placing patients and carers firmly at the heart of health care. It will also explore the possibilities (indeed the necessity) of true collaborative partnership and genuine respect for and use of patients' and carers' expertise and commitment, especially in the management of chronic ill health.

The first priority within *The Heart of Care* programme was deemed to be ‘the invisible army’ of carers. Discussions with representatives from The Princess Royal Trust for Carers led to the decision to plan a one-day workshop for carers, clinicians and managers to promote working in partnership with and to ensure that carers' voices really are heard throughout the publication(s).

The structure of the Engaging Carers workshop was to be based around three questions:

1 What are the benefits of engaging carers as full and active partners in care?

2 What are the obstacles that prevent this kind of engagement?

3 What factors promote engagement?

The day was intended to be educational, certainly, in the broadest sense of the term. It was also intended to provide carers with an opportunity to speak and be heard: to engage in a genuine dialogue with representatives of the health service at various levels, to share experiences and exchange opinions in a safe and contained atmosphere.

The approach to be adopted in the workshop was, therefore, based on sound educational principles (e.g. Gadamer’s vision of dialogue broadening or extending the horizon of understanding) and, perhaps more importantly, driven by a particular set of values. Tony Jeffs and Mark Smith sum up this approach:

> *‘In our view, for something to be called 'education', whether it takes place in the classroom or the canteen, it must be informed by certain values. There is a dividing line between education and indoctrination. Education, unlike the latter, embraces a commitment to:*
>
> *Respect for persons.*
>
> *The promotion of well-being.*
>
> *Truth.*
>
> *Democracy.*
>
> *Fairness and equality.*
>
> *These values should inform both the content of conversations and encounters, as well as our behaviour and relationships as educators. Julius Nyerere once summed these concerns up when he talked of the purpose of education as being the liberation of humans from the restraints and limitations of ignorance and dependency. ‘Nothing else can be properly called education. Teaching which induces a slave mentality or a sense of impotence is not education at all - it is an attack on the minds of men’.*

Taken from Tony Jeffs and Mark K. Smith (1999) *Informal Education. Conversation, democracy and learning*, Ticknall: Education Now Books

Focus of the project

The aim of this research project is to explore flexible approaches to learning and teaching (andragogy) that are more closely aligned with the felt experience of the target group.

I would like to examine what made the day so successful, both from the point of view of the participants and of the facilitators so that we may more successfully emulate the experience. The intention is not to replicate it exactly but to put the lessons we have learned to good use, in the same way an experienced midwife facilitates a good birth, always mindful of the uniqueness of every situation.

This project will help me explore a rather unconventional learning experience and discover:

a) the extent to which participants at the conference have learned anything of lasting value

b) how we can improve the preparation and running of conferences such as this to ensure that every one of them results in such an enthusiastic and heartfelt response from participants

c) how we can develop methods of support and education for carers in ways that are most appropriate an meaningful for them?

In other words, what did we do that was so right and how can we continue to do it so that carers may both benefit from and contribute to society as a whole in a more balanced fashion?

In the service of developing a ‘learning organisation’, this action research project may help us to undertake some double-loop learning as well as improving our andragogy with similar groups of people who do not have regular access to conventional learning.

It will also be possible to find out the extent to which collaborative working in groups assisted learning and helped people to feel supported.

As a result of the project, I hope to be in a position to recommend different ways of working with similar groups of people to enhance the learning of both facilitators and participants.

The project is of considerable interest to me personally for several reasons:

- the unconventional modality of learning and teaching
- a long-standing interest in and exploration of making learning more open and more accessible to adults

- the highly reflective and collaborative nature of the organising group
- shared ideals and values
- a strong commitment to improving the situation of carers
- my own experience of caring.

2 The curriculum and its contribution to informal, experiential and social learning

> *'If you want to build a ship do not gather men together and assign tasks. Instead teach them the longing for the wide endless sea.'*
>
> Antoine de St Exupery

> *'Sometimes, such as when teaching in a classroom, we may have a detailed idea about what we are trying to achieve…. However, a lot of the time we may not have such a clear idea of where things are headed. All we have is a picture of the general direction that we want to go in. However, we set out to foster learning - and this intention is a key characteristic of education.'*
>
> Jeffs and Smith, 1999

According to Jeffs and Smith (1999) 'many of those commentating on informal learning do not seem to make an adequate distinction between learning and education. The latter can be characterized as setting out to foster environments for learning that involve a commitment to certain values such as a respect for truth and for persons (Jeffs and Smith 1999: 12-16).

Although w[1]e were setting out to foster learning, the curriculum for the day was less about learning facts and knowledge and more about shared experiences, inclusivity, collaboration and, above all, process. The stated aim of the workshop was to encourage effective partnership working between several groups of people in order to improve the care offered to both patients and carers, as well as, arguably, to ease the job of the clinicians. We were also keen to recognise and acknowledge the extensive learning and experience of the carers who attended the day.

We (the organisers/facilitators) hoped to learn as much as (if not more than) the participants, believing, along with Gessner (1956) (and doubtless many others), that 'the adult experience counts for as much as the teacher's knowledge'.

> *'Our curriculum conceptions, ways of reasoning and practice cannot be value free or neutral. They necessarily reflect our assumptions about the world, even if those assumptions remain implicit and unexamined. Further, concern with conceptions is not "merely theoretical". Conceptions emerge from and enter into practice.'*

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[1] The use of 'we' reflects the collaborative nature of the working group and relates to aspects of the project that were discussed, decided and implemented by this group. The work on this paper and the words in it are entirely mine, except where otherwise indicated.

Cornbleth (1990)

Naturally, our ‘curriculum’ was shaped by our own perceptions, experiences, ideals and values as well as our commitment to genuine collaboration and co-operation. Barkatoolah (2002) and many others have highlighted the importance of **process** in what might be broadly termed ‘adult education, and this was certainly the focus of our day.

Wenger’s (2000) model of social learning that ‘combines personal transformation with the evolution of social structures’ provides the theoretical underpinning for our work and informs our attempts to promote engagement, imagination and alignment through ‘boundary interactions’ in our desire to bring about social as well as personal change.

Nevertheless, there was a ‘theoretical’ element of the curriculum, enshrined in the three questions (see above and Appendix 1), the answers to which we hoped would lead to some enlightenment as to the nature of carers’ experience at the interface with healthcare and how this might improved.

Target learners

Three groups of learners participated in the workshop:

1) unpaid carers

2) health professionals (including managers and decision-makers)

2) the organisers/facilitators of the workshop.

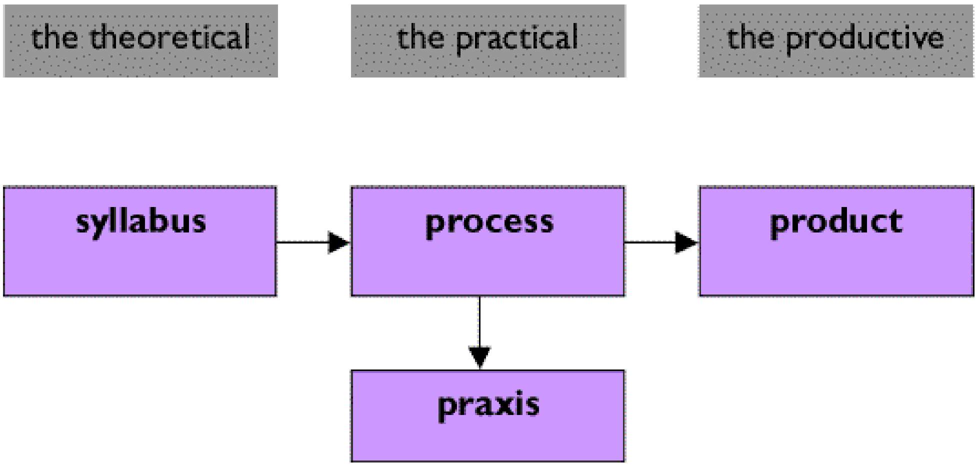
We were keen that all three groups should participate in the learning during and resulting from the day.

Significant combined experience of working with adult learners had led us to our own understanding of certain assumptions about adult learners (as summarised in section 11 of the paper on Investigating the theories and based on the work of Malcolm Knowles):

- Adults are motivated to learn as they experience needs and interests that learning will satisfy; therefore, these are the appropriate starting points for organising adult learning activities.
- Adults’ orientation to learning is life-centred; therefore, the appropriate units for organising adult learning are life situations, not subjects.
- Experience is the richest resource for adult’s learning; therefore, the core methodology of adult education is the analysis of experience.

- Adults have a deep need to be self-directing; therefore, the role of the teacher is to engage in a process of mutual inquiry with them rather than to transmit his or her knowledge to them and then evaluate their conformity to it.
- Individual differences among people increase with age; therefore, adult education must make optimal provision for differences in style, time, place and pace of learning.

Perhaps the curriculum model for our carers' day is most usefully examined in the light of the following diagram (Smith, 1996, 2000), which seeks to encapsulate Aristotle's three categories of knowledge, and the resulting curriculum models.



Education, like many other areas of human endeavour, is largely measured these days by '**product'**, influenced by the thinking of Franklin Bobbitt and Ralph Tyler.

> *The central theory [of curriculum] is simple. Human life, however varied, consists in the performance of specific activities. Education that prepares for life is one that prepares definitely and adequately for these specific activities. However numerous and diverse they may be for any social class they can be discovered. This requires only that one go out into the world of affairs and discover the particulars of which their affairs consist. These will show the abilities, attitudes, habits, appreciations and forms of knowledge that men need. These will be the objectives of the curriculum. They will be numerous, definite and particularized.*
>
> Bobbit (1918)

Certainly our day was based on an exploration of the 'particulars of the affairs' of carers, although not, perhaps, exactly a desire to help them in the performance of their 'specific activities'. Our intended tangible product remains a publication based on the day, including the many insights and words of wisdom provided by the carers.

But this was not really the most appropriate curriculum model for our day.

Nor did any **syllabus** form the primary focus or represent the main curriculum model. However, we did provide background information and history about the carers' agenda and the growth of carers' rights over the past 50 years. Our concern in this respect was to make sure that this information was conveyed sensitively and effectively and hence our preference for andragogy as a *modus operandi*, rather than pedagogy.

The curriculum models which most informed our day were those of **process** and **praxis,** as described by Smith (1996, 2000). We were most concerned to 'encourage conversations between, and with, people in the situation out of which may come thinking and action.' Further, we wished to promote an ongoing evaluation of the process and 'what they can see of outcomes'. We wanted people to create their own meaning from the day and find a place for new learning in their own lives and our hope was that 'the dynamic interaction between action and reflection' would lead to the kind of committed action described by Smith (1996, 2000) in his praxis model of curriculum.

> *'That is, the curriculum is not simply a set of plans to be implemented, but rather is constituted through an active process in which planning, acting and evaluating are all reciprocally related and integrated into the process'*
>
> Grundy, 1987

At its centre is praxis: informed, committed action. Although we hope this action is 'informed by theoretical study and personal and practitioner reflection' (University of Ulster, Flexible Curriculum Lecture 3), it is instructive to note that

> *'In praxis there can be no prior knowledge of the right means by which we realize the end in a particular situation. For the end itself is only specified in deliberating about the means appropriate to a particular situation'*
>
> Bernstein, 1983

In accordance with this understanding of curriculum, the values and methods we employed in organizing and running the day were 'more concerned with collective understandings and practices and to structural questions'. Our process took people 'beyond a focus on individual attitudes and encouraged them to confront the material conditions through which those attitudes are constituted' by helping them to realize the collective nature of the feelings that carers experience as well as the supportive nature of the group.

Our first exercise laid the foundation for this process. Following a brief introduction outlining the day, we upheld our promise to ourselves to provide a space to air the difficult, painful or angry feelings that participants might experience. Monica, our Patient and Carer Experience expert, spent a very short time introducing herself and her own experience of caring for her husband who had suffered a severe stroke. She knows only too well how it feels to lose a sense of oneself as a woman, as a wife, as a person and to be left feeling only like a carer.

She then went round to each person in the room asking them to name a feeling that she or he experienced on a typical (bad) day of caring. No distinctions were made between ‘carers’, professionals or facilitators. After the first few responses, the repetitions began and gradually tears and knowing smiles indicated an acknowledgement of the common experiences, the shared suffering of the group. Anger was, as Monica had predicted, the most commonly admitted feeling.

The next task was for each person to identify his or her strengths and, once again, each person in the room, was asked to say one good thing about him or herself and, once again, the same and similar qualities were identified.

Although this session had taken 15 minutes from our schedule, its value was incalculable. Monica’s honest sharing and open questioning, combined with her ability to engage with people, allowed everyone to air difficult feelings in a safe environment and recognize that they were not alone.

3 ‘Continuity and context’: inclusivity, relevance and effectiveness of the learning provision

> *The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life - the sick, the needy and the handicapped.*
>
> Hubert Horatio Humphrey, US Vice President

Clinical Governance aims to assure the safety and quality of care as well as to transform existing models and patterns of care in order to realise the values of equity, respect, humanity, and justice.

Bearing in mind these values, which lie at the heart of all our work, and mindful of the need to provide an appropriate environment for the kind of reflective and reflexive learning that we hoped would occur during and after the day, considerable thought was given to arranging every aspect of the day. Aware of the particular needs and constraints of carers (especially time and financial constraints as well as the need for respite care), it was important to find a venue that was trustworthy and accessible (easy to find and get to and able to accommodate a range of special needs) and, perhaps most importantly, to ensure that workshop participants felt valued.

Vygotsky (1978) recognised the dynamic process of learning within the individual’s immediate context and suggested that this context provides its own challenges. The individual’s consciousness, according to Vygotzky, is the **product** of learning, as the previously internalised learning becomes a set of tools for new thinking and learning. In this way the process of learning produces further learning capability: this is similar to the process which is so admirably reflected in Kolb’s familiar learning cycle.

The effectiveness of the learning is inevitably influenced by the extent to which it is inclusive, accessible and relevant to the learners, or carers in this case. In our attempt to provide a suitable context for learning, meticulous attention was paid to the organisation of the workshop, with particular focus on:

- an appropriate mix of participants in terms of age, ethnicity, condition affecting the person cared for
- careful balance between carers and professionals
- timing (the need to arrange respite care meant that we could not start to early nor end too late)

- provision of information (we made sure that plenty of information was available to all participants before the workshop, to enable informed decisions as to whether to attend as well as to guide expectations of the day)
- possible sensitivities around identity and intimidation (we wanted to avoid an ‘us and them’ situation between health professionals and carers),
- the mix of people at tables
- provision of (pre-paid) travel tickets and accommodation for those travelling from a distance
- intention (and wherewithal!) to pay expenses on the day
- how to record the day (we adopted the belt-and-braces approach of appointing a facilitator to write notes for each table, placing a mini audio recorder at each table, engaging the services of a video camera-man to make a wandering ‘account’ of the day, as well as capturing the thoughts of individual carers on post-its and those of the table groups on cardboard hexagons (ref book about hexagons).

Despite invitations being sent out only four weeks before the workshop date (a result of summer holidays combined with our attempts to ensure the right mix of people), 47 people attended the workshop, broken down as follows:

22	Carers and ex-Carers
7	Carers Development Workers
4	NHS Managers and Clinicians – these included an Executive from a Ambulance Trust, a Pharmacist, two Doctors and one clinician/researcher who was also a carer
9	Facilitators from NHS Clinical Governance Support Team
2	Facilitators from The Princess Royal Trust for Carers
1	Facilitator from Pilgrim Projects
1	Facilitator that will be producing the digital stories from the day

Participants were all in agreement with the stated aims of the workshop: previous conversations with individuals had revealed a genuine commitment and desire to find ways of more effective working between carers and health professionals, to benefit not only their patients, but also themselves and society as a whole. In terms of learning provision, then, our main task was to facilitate the process that would lead to more open and equal dialogue between patients and healthcare providers.

We viewed the workshop as but one episode in the journey towards better care, not unlike Dewey's notion of learning as a continuous process:

> *'the principle of continuity of experience means that every experience*
> *both takes up something from those which have gone before and modifies*
> *in some way the quality of those which come after ...'*
>
> Dewey (1938)

Great care was taken to ensure that participants felt comfortable and at ease. Participants were greeted as they arrived and presented with a personalised pack, containing the agenda for the day, some reading material, a letter from the Deputy Chief Medical Officer thanking them for their participation, list of participants, evaluation form, information about the Patient (and Carer) Voices programme, together with a consent form for those wanting to participate.

Our Patient Experience representative had advised us that carers attending such an event often value the opportunity simply to meet and talk to other carers as much as any other aspect of the day. Further, she had suggested that it could be a good idea to allow an opportunity to deal with the feelings of anger and frustration with which most carers are familiar.

This kind of meticulous attention to practical details also ensured that the learning experience was a holistic one; experienced through the mind, the body and the heart. Although it is perhaps a rather grandiose claim to make, our aim was to emulate Waterhouse's 'continuously supportive process which stimulates and empowers individuals to acquire all the knowledge, values, skills and understanding they will require throughout their lifetimes and to apply them with confidence, creativity and enjoyment in all roles, circumstances and environments (Waterhouse, 1996).

Further, it is important to note that our focus was not on teaching but rather on learning. Even the 'main' presenter was focused on the facilitation of the process, ensuring that it fostered co-operation and collaboration and followed the traditions of Delphic enquiry.

It is worth pointing out at this point that several of the organisers had attended a similar event, relating to Patient Participation, the previous week. We had observed that participants were angered and frustrated by the lack of opportunity for them to express their feelings and their views. The schedule/agenda for the day was rigidly adhered to, with much watching of clocks and insistence on keeping to time and to task, rather than acknowledging the strength of feeling and wealth of experience in the room. What people seemed to have learned from that day might be summarised in the old American Indian saying that ‘white man speak with forked tongue’ – there was a disjunction between what was apparently offered and what was delivered.

That day was pervaded by negative feelings and we determined to do whatever we could not to replicate such a situation. Our initial session, intended to ‘harness’ some of the negative feelings, was prompted by that day and the realisation that a simple acknowledge of the ‘dark’ side of caring could make an enormous difference to the participants.

Thus, our first session, as already described was, we felt, key to avoiding the kind of hostility, resentment and cynicism that are all too common the result of well-meaning events ostensibly organised to gather the views of participants but which seem, in reality, to make little change.

Throughout the day our focus was on facilitating those conversations that would lead, hopefully, to understanding and, ultimately, to collaborative working. This method of working with adults is based on theories, models and techniques of a number of people, including the ideas and practical suggestions of a Quaker doctor called Rachel Pinney who developed a technique called *Creative Listening*. She outlines the necessity for complete attention and genuine listening as a precursor to genuine understanding. She further contends that, in a situation where there are two opposing points of view, if there is true listening, only the view of one side will need verbal expression. Her ideas have been particularly useful in contexts such as psychotherapy and pacifism, but are echoed in these words of Hans-Georg Gadamer (1979):

> *‘[Conversation] is a process of two people understanding each other. Thus it is a characteristic of every true conversation that each opens himself to the other person, truly accepts his point of view as worthy of consideration and gets inside the other to such an extent that he understands not a particular individual, but what he says. The thing that has to be grasped is the objective rightness or otherwise of his opinion, so that they can agree with each other on a subject.’*

While we might disagree about the intrinsic rightness or wrongness of an opinion, the need for a genuine commitment to listen in order to hear and understand and expand what Gadamer calls ‘the horizon of understanding’ was fundamental to planning the day.

Broadening the curriculum: using ICT

Another aspect of our curriculum planning, and part of our avowed aim to give carers a voice, was to provide an opportunity for participants to engage in our Patient Voices programme. This consists of a series of short videos of patients and carers telling stories of their experiences of the health service which can be seen at http://www.pilgrimprojects.co.uk/clients/nhsma/pv/index.htm

The first element was the filming of the day. As part of the introduction to the day, participants were told that we intended to film the events of the day and their consent was sought. Contingency plans were in place for dealing with anyone who was reluctant to be filmed, but these proved to be unnecessary as everyone was enthusiastic about the opportunity to create a record of the day.

In addition, all participants were invited to let us know if they would like their own story to be filmed. Information and consent forms were provided and most participants completed these. A programme of filming has yet to be implemented.

Part of the success of this aspect of the day was undoubtedly due to the discretion and experience of the cameraman, who quietly and unobtrusively circulated around the tables, capturing snippets of conversation which were subsequently woven into the first cut of the video highlighting the main messages from the day.

A number of participants saw the potential for using this medium to ‘broadcast’ their stories on the Internet so that other people might be educated in the needs and experiences of carers. Following the workshop, participants and organisers have continued to use email to share ideas and information. Some other ideas for exploiting the potential of ICT are explored later in this paper.

4 A critique of the curriculum and suggestions for enhancement

> *'Dialogue is the encounter between men, mediated by the world, in order to name the world.'*
>
> Paulo Freire

In order to capture the rich contributions of the carers we did the following:

- captured the entire conference on video, via a 'roaming' cameraman filming the various tables
- set out mini audio recorders on the tables to record the conversations
- input all the sticky notes that were posted in response to some of the interim questions
- captured recommendations arising from table discussions on cardboard hexagons and subsequently input them
- input notes taken by table facilitators
- provided an evaluation questionnaire for the day itself (see Appendix 3 for a summary of responses).

This means that we have audio, video and electronic records of most of what was said on the day, as well as written records of carers' ideas and aspirations and some conversations between participants.

One follow-up meeting of several of the organisers/facilitators was held after writing the first draft of the publication, in order to review progress. This meeting provided an opportunity to reflect on the process and identify what we had done that had resulted in so many carers referring to the day as the best event of its kind they had ever attended.

In addition, I subsequently:

- sent out a questionnaire to all participants, including facilitators, three months after the event with the questions set out in Appendix 1
- followed up with several phone calls to participants whose responses were particularly note-worthy.

The personalities and tendencies of the organisers, combined with a strong commitment to improving the situation for carers, predisposed our team to reflection and consideration of ways to improve such events, or to do more of what we appeared to do successfully. Some of their thoughts are reproduced in Appendix 00.

Several participants responded to the questionnaire in fulsome terms: some of their feelings and thoughts are included in Appendix 2. Their suggestions for improvement were minimal and fall generally into the category of organisational requirements, such as:

- a preference for more information before the day
- request for more time to complete written statements
- somewhat ambivalent comments that it might have been nice to know more about the other participants
- more notice of the day
- more information about the venue.

However, one carer with whom I have corresponded but who did not actually attend the day has pointed out that goodwill and positive feelings rapidly fade when faced once more with the endless and thankless task of caring and has urged us not to replicate the experience of so many similar events which have, in the end, no real outcomes.

Our curriculum experience was based on the social, constructivist model as described in the lecture for Theme 3: Self-assessment and evaluation. Our aim could be described as helping participants 'use the perspective of other persons, both individual and group perspectives, to clarify and expand on their own thinking and conceptualisation of ideas' (Joyce et al 2002:31) while employing a dialogue to enable participants to reach an understanding of the thinking of others (Gadamer). In this, I believe we were successful.

Laurie Thomas and Sheila Harri-Augstein (1991) follow in the wake of Gadamer and Socrates before him who have realised that dialogue is necessary part in order to facilitate learning and to unravel our own assumptions in order to enable understanding of another's position. Their approach to self-directed learning is framed as a 'learning conversation', in other words, the conversations we have with ourselves or with others that help to clarify our thoughts, direct and draw attention to our learning. These conversations are actually going on all the time, internally as well as externally, with colleagues, peers, teachers, supervisors, mentors. We need to recognise these conversations for what they are and make use of them as the basis for structured reflection.

Further, the organisers/facilitators' collective insight into the mental models and world views of the participants enabled us to customise the curriculum to their knowledge, with an 'emphasis on hands-on problem solving and the integration of new models and innovation.'

We facilitated the process of making connections between facts leading to new understanding, primarily of each others' experiences, with encouragement to participants to discuss and analyse the information that was shared during the day through extensive dialogue.

I have already described what Gadamer calls the 'moral and ethical commitment to understanding the values and meanings held by the other person', recognising that any knowledge to be gained would result from personal engagement. This seems also to concur with Hogan's (2002) 'emphasis on teaching and learning much more as a matter of an interplay with overt and unseen consequences than a matter of transmission of cognitive content and values.'

In view of the high praise from many participants, it seems that our task in evaluating the experience is more to discover what we did right, in order to do it again, than what we did wrong. Nevertheless, there is always room for improvement and we would certainly bear in mind some of the comments as well as our experiences when organising future events of this nature.

Some of our logistical arrangements, such as seating allocation and an initial plan to move people at lunchtime, were unnecessarily complicated and intrusive. Facilities for people with impaired mobility could have been improved, but this resulted in a misunderstanding with the venue, which of course would be rectified another time.

Other ways of ensuring that carers felt valued and that lessons were being learned from the day included a letter from the Deputy Chief Medical Officer acknowledging their participation in the day and a follow-up letter from the Head of the Modernisation Agency to inform participants of subsequent developments.

There is, it seems, little we would do differently except, perhaps to organise more similar events. The process of Affirmative Enquiry, identifying the 'good' things about the process and each other, has proved to be a valuable tool in acknowledging the truly collaborative nature of the organising team. It felt at times like an orchestra, consisting of a number of people playing different instruments but who came together for this performance, under the leadership of a skilled conductor who acknowledged the talents of each person. Each individual played his or her instrument to the best of her or his ability, but in the service of the concert as a whole and a harmonious and timely performance was the result.

5 Evidence from the research: informing analysis

> *'Culture of the mind must be subservient to the heart.'*
>
> Mahatma Gandhi

A brief review of the responses to the evaluation forms (included in full in Appendix 4) included the following comments:

- Lots of pre-consultation with everyone working closely together ensured peace of mind.
- Everyone who commented said the workshop met their expectations and was well run and some lovely comments were noted.
- Some participants would have liked more details of who everyone was – we had thought of giving everyone an attendee list with people's titles on but thought it might be intrusive to do so – so we took off the titles and companies names for privacy.

Everyone who commented felt they went away with good feelings.

Unfortunately only 13 evaluation forms were completed. This may have been because some people had to leave very promptly and the questions required some thought. Next time we need, perhaps, to make sure that these are completed at the time, or we need to include a stamped envelope asking people to return completed forms to us.

Although having written records is important, on the other hand, we learned a good deal from unwritten comments and we would like to build on what Monica Clarke has referred to as 'the culture of the non-written critique'. Questionnaires are not always the best way to gather information. So many insightful and instructive comments were made on the day and we were able to harvest many of these through video and audio recording.

Some of the other issues highlighted by questionnaire respondents were those with which we too had grappled, the chief amongst these being the degree of anonymity to be accorded to participants. In our attempts at equity, we had decided that name tags should contain names only, with no mention of jobs, job titles or organisations, in order save possible embarrassment on the part of people who had no 'official' job title. I am still uncertain about this.

It seems, then, that there were no criticisms of the curriculum part of the day or of the experience we had intended to provide.

We were also uncertain about how much information to provide before the day. While wishing to provide sufficient information to enable informed choices to be made about attendance, we did not want to predispose people or raise unrealistic expectations. We could, however, have sent out invitations earlier, and this might have ensured higher attendance from health professionals.

We are still in the process of editing the video, hoping to end up with no more than 10-12 minutes distilling the essence of the day and summarising its main points. Our intention is to show not only the 'events' of the conference, and what was said, but also to indicate our own learning from the event by turning the camera around, as it were, to look through the other end of the lens. In this way we hope to capture the process learning of the facilitators as well as the learning from the carers' experiences.

As a result of beginning to write the first draft of the book and the recognition that it would provide little (if anything) that wasn't available elsewhere, we determined to change our approach completely, so that we can share the process – how we felt, what we've learned – as well as the outcomes.

A meeting of some of the organisers, together with comments from participants, led us to recognise the unusual nature of the day. We determined that the most valuable contribution we could make, and the best way we could serve the carers was not only to write up the many excellent and heart-felt ideas expressed on the day, but also to include whatever we have learned about the process of running such a day that provoked such positive responses from all the participants.

Some thoughtful heart searching led to comments such as the following:

> *'Although I was keen to stick to the agenda, and concerned about the timing, I'm so glad Monica followed her intuition and engaged with participants in the first session. If we had proceeded in the 'conventional' way, according to our plan, the flavour of the day would have been completely different and I doubt whether we would have captured the emotional quality of the carers' experiences. Monica completely won them over and gained their trust.'*
>
> Paul Stanton

6 Evaluation and suggested improvements

> *'When will our consciences grow so tender that we will act to prevent human misery rather than avenge it?'*
>
> Eleanor Roosevelt

The facilitation of learning, much like the facilitation of the development of a book has been likened to midwifery and the birth of a baby. I would like to think that our carers' day exemplified this process, assisting the birth of something new. Our guiding values, beliefs and behaviours with this group seem to have fostered healthy group working and learning, through the development of new roles and an enlivening group culture which, we hope, will lead to transformational change (McMorland and Piggot-Irvine, 2000) as a result of the collaborative and co-operative labour. Like that of a midwife, our role has been to facilitate and manage the process so that the individuals and the group will feel empowered to make changes in their own lives which will spread out to influence other carers, patients and members of society.

The empirical evidence suggests that, apart from practical improvements such as better sound systems and larger posters, the curriculum part of the day went better than any of us might have anticipated. In this respect, perhaps the most important improvement would be to offer more events like this one, for patients and carers. Our process succeeded in facilitating open and honest dialogue which enabled people to share experiences, views and opinions, and appreciate the contributions of others. It helped people to realise that they are not alone with their anger, fear, anxiety, depression and pain, but that there are many others who share these very human experiences. But perhaps most importantly, we helped people to value themselves. It is particularly important that this unpaid army of carers realises its own worth, so that, as a society, we too may recognise the significant contribution they make to our healthcare system.

In structuring and beginning to write the book, we realised that there is actually much that has already been written, in particular by the Princess Royal Trust for Carers and it is foolish to keep on reinventing similar wheels. In the meantime, we have realised that there were a number of factors that contributed to the success of the day, including:

- a deep and genuine passion on the part of those involved in organising the event to make things better for carers and the people for whom they care
- open-mindedness and flexibility with respect to the agenda (it was the servant rather than the master of the day)

- real respect, appreciation and acknowledgement of the wide range of skills and talents brought to bear in the organisation of the day
- acknowledgement of powerful carers' feelings - and an opportunity to 'park' these at the beginning of the day
- excellent table facilitation.

Recognising these factors has led me to think not only about the need for a range of different qualities in a team but also about some ways of mobilising for change and the need to engage people's hearts and souls (as we try to do in our Patient Voices stories). Some research into this area has been done by Professor Helen Bevan, but more could be learned about the qualities of some mass movements that have people flocking to join them. It is only partly about leadership, but also about the degree of passion that is aroused in people about the particular issue, whether it is race, or gender or sexual orientation or non-violence.

Brenda Zimmerman and Brian Hayday (2003) have developed the notion of ‘Generative relationships’ – those relationships that ‘occur when interactions among parts of a complex system produce valuable, new, and unpredictable capabilities that are not inherent in any of the parts acting alone’. This model has offered a constructive way of thinking about how we might develop teams in the future.

The generative star (illustrated in Appendix 5) consists of the following elements:

Separateness or differences - how are these manifested?

Talking and listening OR Tuning -what might be done to promote such tuning?

Action opportunities - what might you do to start?

Reason to work together (what might be used as a ‘frame’ for working together?

In a presentation about mobilising for social change, Helen Bevan (2004) of the Modernisation Agency reminded us of Antoine de St Exupery’s wise words from *The Little Prince*:

> *'If you want to build a ship do not gather men together and assign tasks.*
> *Instead teach them the longing for the wide endless sea.’*

And so we have changed our ideas about the book we will write. Our thinking now is to write about the process and what we have learned from it. We hope to be able to describe our particular and unique experience, with contributions from all the people involved and to generalise some broader lessons from this that could be useful to many people in the NHS, for example:

- the need to take care in all that we do
- the need to listen deeply and carefully to others (and in particular to patients and their carers)
- the need to be flexible and responsive
- the need to acknowledge the multiplicity of skills and talents that go into making such an event work (or otherwise).

Such a publication might not be unique but would, I believe, help to shift the focus from product and outcome to process and the real source of change, bringing to mind words from a poem by Derek Mahon: 'The hidden source is the watchful heart'. In our attempts to bring about social change, we awaken a new understanding and come to a new awareness of what really matters. As Michael Jones (2004) says:

> *'Beauty and the sense of belonging it evokes introduces us to a new standard of care--a quality of attending-- which we may extend to our sense of stewardship in creating communities of care. Perhaps in the future a well lived life will involve the shift from a focus on utility to the combined search for signs of the beautiful.'*

And perhaps this is where transformation begins.

Everything is going to be all right

Why should I not be glad
To contemplate the clouds clearing beyond the dormer window
And a high tide reflecting on the ceiling
There will be dying,
There will be crying, but there is no need to go into that
The poems will flow from the heart unbidden
And the hidden source is the watchful heart
The sun will rise despite everything
And the far cities are beautiful and bright
I lie here in a riot of sunlight watching the daybreak and the clouds flying
Everything is going to be all right.

Derek Mahon

7 Personal and professional development, reflection on the research analysis and a plan for the future

> *'Knowing ignorance is strength; ignoring knowledge is sickness.'*
>
> Lao-Tzu

Personally, I have been able to reflect on my own role as a carer for my father in a more analytical fashion and to consider how I and other individuals and agencies might have done this differently/better. I was pleased that my own recent experiences helped me to feel more aligned with the carers: indeed, everyone present on the day had experience of caring and so the feeling of 'us and them' was significantly diminished. It was sobering to be reminded of the universality of the caring experience.

Professionally, I was privileged to be part of such a committed, passionate and multi-disciplinary team with a mind-boggling diversity of skills at their disposal. I was reminded of the importance of valuing the skills of everyone involved.

I have been reassured about the almost endless potential from such a gathering. The energy and goodwill engendered by the day were heart-warming and incredible, as was the gratitude of the participants for things that seemed to be only human or, at the very least courteous. If what happened during our carers' day was remarkable, then the qualities that we might expect in an activity as universal as healthcare, such as compassion, respect and justice, must be in remarkably short supply. If a genuine passion for collaboration and desire to improve matters for carers can engender so much goodwill, then there is hope for all of us experience the health service, whether as patients, carers or 'professionals'. This is the stuff that social change is made of.

I have been reminded that the outcomes are not necessarily those that are planned or expected. Important outcomes from this conference include a significant degree of networking and collaboration between carers and professionals: Monica Clarke (2004) has hailed this day, its organisation and what has resulted from it as 'a new way of collaborative working – from the heart – a way of working for the future.'

However, the emphasis on the importance of process must be balanced against the need for genuine outcomes that will improve carers' lives. These words from a carer, received only yesterday, were a powerful message that we must continue to move forward and resist any inclination to view the process as more important than the outcomes.

> *'In my experience, within weeks, if not days, the good feelings generated by a successful conference dissipate, unless the carers see for*

> *themselves a significant attitude change, and that is where I for one would like to see the focus. At the very most, the good feelings give enough pep to an already exhausted person to go home and start battling against the odds again. But it can't last because the carer is already exhausted.'*
>
> Carer of an adult daughter with learning disabilities

The workshop and follow-up work has been a lesson that, despite the difficulties of achieving things under the umbrella of a large organisation such as the NHS, change does happen, and there has been progress on the carers' agenda, so there is hope for further change and improvement.

People are very willing, even eager, to tell their stories. I believe, along with Monica Clarke that, by facilitating the telling of stories and then asking the question: 'How might this have been different?' or 'What would improve this situation?', we have helped to hasten the process of change. This begins, of course, with the changes that occur with each individual as he or she recognises that some of the responsibility for change rests within. By encouraging people to think in this way, their stories are moved on - to another page or even another chapter.

I believe that the stories we have captured in the Patient Voices programme, which seem to resonate so strongly with carers and patients as well as with healthcare professionals, also help people to re-evaluate and ask themselves the question: what can we do differently – how can this be improved?

I realised at first hand that money is extremely tight for many carers, and some people could only attend if their expenses were paid in advance or refunded in cash on the spot and if respite care was arranged. We further learned that it was necessary to take along a large cash float for this purpose – we also learned how rare this is, as so many carers were both stunned and extremely appreciative.

It has been sobering to be faced with people who have done so much and yet have so little faith in themselves. If our conference has helped some people to value themselves more, that is more than adequate reward for our work.

Rereading some of the course materials and reflecting on my own learning and development through this process led me, by a slightly circuitous thought process, to the notion that education should simply be free. No one would then be disadvantaged by age or disability or poverty: access and inclusion would be universal. This somewhat idealistic notion led me to consider the particular needs of carers and gave rise to the vision of using ICT to provide learning opportunities and support to carers who, because of their caring duties, the need for respite care and scarcity of funds, often find it difficult to get out.

Such a scheme would provide the ultimate in flexibility with respect to the curriculum, an enormous potential for collaborative learning with the consequent widening of the horizon resulting from the potential to engage with carers everywhere. The potential for learning is enormous with the learner/carers contributing to the knowledge and experience base as well as benefiting from the knowledge and experience of others.

My own experience of collaborative learning and sharing of ideas and experiences both through this course and other specialist 'newsgroups' to which I belong has been immeasurably enriching, providing the opportunity to exchange ideas with people I might never meet but with whom it is possible to forge strong bonds through the ethereal medium provided by the internet.

Perhaps the most important learning for me has been the reminder that it is easy to think you understand other people's problems, to make assumptions – and even attempt improvements – accordingly. It is more difficult to remain receptive and simply listen to the stories of suffering and heartache with an open heart and mind. According to the Buddha, the way out of suffering is through suffering. A willingness to hear the sadness and the pain is the first step towards understanding the suffering of others and a necessary precursor to the cultivation of compassion which in turn may give rise to the actions that may alleviate that suffering.

Other skills/learning

Some of the other things I learned include:

- It's good to use several techniques for gathering information, including some that are more contemporaneous).
- It's better to use boundary microphones than directional microphones.
- The smaller the group, the easier it is to identify recorded voices (for the purposes of making transcripts).
- Be sure to ask permission for audio recording as well as video recording.
- It is not be possible to gather all the information from such a day on one video, but a multiplicity of approaches may be more appropriate for dissemination.
- Audio and video records can be as important as important as the answers to questionnaires and evaluation forms.
- Process really IS as important as outcomes, but it is not necessarily MORE important.

- People really do learn as much from each other as from the curriculum and the facilitators.
- Working in a multi-disciplinary team in the spirit of trust, respect and collaboration really can be productive, as well as enjoyable.
- Follow-up support and communication is always important in educational activities, but particularly so for this group of people.
- Active (or deep) listening really is the first step towards understanding.
- 360 degree feedback is a valuable and reassuring process, in a truly collaborative group.

Development plan

> *'We must be the change we wish to see.'*
>
> Mahatma Gandhi

Many of the proposed actions set out here are the results of a brainstorming session held on 25th January, 2005 with my colleagues on the Engaging Carers core team. Although this is a list of practical things that could be done, the overall aim is to find ways of working with patients and carers that embody the principles of humanity, equity, justice, respect, collaboration and compassion.

Possible actions include the following.

- Disseminate the findings set out in this paper, so that our 'process' is acknowledged and might inspire others to work in similar ways.
- Recommend the development of a planning framework for workshops with carers (and patients) that promotes collaborative working, active listening and flexibility in response to the needs of the participants.
- Encourage the use of what Brenda Zimmerman calls 'wicked questions': those difficult questions with no set answers with an inherent paradox or tension embedded in them that are intended to reveal underlying assumptions by opening up different options and lines inquiry and bringing to the surface the fundamental issues that need to be addressed.
- Explore a variety of ways to increase public awareness of care and carers, including:
  - a television programme or programmes

  - produce more digital stories of carers' experiences that could be available on the Internet
  - publicity and public relations activities, such as beer mats or fliers posing three questions about carers with a website address where people would find 'the answers'.

- Develop the idea of mass mobilisation for social change:

  - explore how we might use some of the lessons from great social movements and

  - identify the characteristics of good leadership necessary to guide a 'grass roots' movement of this nature.

- Initiate a wider exchange of experiences between carers and decision makers, so that each side will have a greater understanding of the other :
  - empower the 'invisible army of carers' to go out and interview people on their attitudes to and experiences of care and carers.

- Use ICT and digital stories as the basis for an open/distance/e-learning education programme on implementing quality care, targeted at (and clearly differentiated between):
  - carers
  - patients
  - clinicians (including community matrons and practice managers)
  - administrators
  - managers
  - NHS Trust Board teams.

- Explore linkages with the lifelong learning agenda.

- Develop educational materials highlighting the kinds of skills that are necessary for carers (practical skills such as lifting, budgeting, benefits and nutrition as well as 'softer skills' relating to social change and the health and social care agenda) perhaps to align with the lifelong learning agenda.

- Include carers (50% of membership) in all planning and all working groups pertaining to the carers agenda, in contrast to the 'old' consultation way of working which did not really include carers in the planning process.

- Plan a high profile launch to heighten public awareness of the inestimable value of carers and the unpaid work they do in our society.

A scoping exercise is now underway to explore the possibility of establishing an Internet portal which would offer opportunities for dialogue and engagement in a number of ways.

The intention would be to establish a pilot with a number of carers around the country who would be provided with broadband Internet access (and computers if necessary). The site would:

- provide a gateway to references, resources, sources of information, news, etc
- link to government policy and legislation.
- offer opportunities for asynchronous discussion and synchronous chat
- permit synchronous discussion using Voice Over IP (Internet telephone calls).

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Appendix 1: Engaging Carers' Programme for the day

10:00 Introduction and key issues

10.20 Listening exercise
What are the key issues for carers?

10:40 Statutory rights and entitlements of carers

10.50 Group exercise I
What are the benefits of engaging carers as full and active visible partners in care?

11.20 Coffee & comfort break

11.40 Carers' stories

12.00 Group exercise II

What are the obstacles that prevent full, active and visible engagement of carers?

12.45 Lunch

1.45 Group exercise III
What factors promote the active engagement of carers?

2.30 Key messages (to)

The Department of Health

The National Programme for Information Technology

My local hospital

My Mental Health Trusts

My Carers Organisation

The Government

My Local General Practice and Community Nurses

My Ambulance Services

My Social Services

3.15 Final pairs exercise
Things I have learned or have enjoyed

3.30 The next steps

4.00 Tea and end of the day

Appendix 2 Questions for carers and some responses

1 Have you attended similar conferences/workshops in the past?

2 Was this event similar or different?

3 If the latter, what made it different?

4 Did you learn (or benefit) more or less as a result of the difference?

5 How helpful did you find the collaborative elements of the day (working in your table groups)?

6 What did you learn from the day or, to put in another way, what has changed for you as a result of the conference or how have you benefited?

Participants' responses

Here are some responses to the questionnaire:

What made this day so different from other similar events?

'I came away from the day feeling v. energised, positive, with a huge sense of really practical and personalised ideas of how the care agenda could be turned into practice...' coming from the carers, rather than being a policy document.'

'Hugely safe environment.' Very friendly – friendly atmosphere as soon as you walked into the room. People used first names (even Paul). There were people on the door to greet you.'

'The day was very logical – in an emotional way, going from looking at the negative things, then the positive emotions, transferring that into challenges, then looking at where we go from there.'

'The day was genuinely carer-led with few preconceptions about what might come up, and the questions were about our contribution, not about how we felt about things that were being done for us, or to us, or to our loved ones, by 'agencies' or 'professionals'. So often, 'consultation' is about things that are already decided, or nearly so, and if we're lucky we might get a choice of two pre-decided possibilities. Or we're allowed to dream, but told our preferred option is too expensive or something.'

'There was a real sense of carers as contributors to the system, and not just an annoying adjunct to the professionals, with an acknowledgement of the specialist knowledge and power that we all have**.** (That said, that's how we all felt on the day, but translating that into policy and practice will be a different and more difficult matter).'

'The post-its allowed stuff to be captured even if it was slightly 'off-topic', so no thought was lost, and no topic was declared irrelevant **-** we were gently steered back to the topic in hand, but nothing was dismissed (c.f. the Scot Exec thing I've just been to , which was to talk about clarifying the wording of the code of practice for the Act, and not the consequences of the Act itself, which I'm sure a lot of parents were more interested in!!) And common themes emerged from different people writing similar things**,** but it was fascinating to see how people had a slightly different angle on those themes (er, can't think of an example, but it must be all there in your notes).'

'Being put into groups is always helpful, right from the beginning – anything that facilitates people talking to each other is always a help. Name badges with only first names stimulated questions about where people were from, etc.'

'It was very helpful. I learned and benefited so much more as a result of the differences. I found working in the morning table group of immense benefit, being able to express my feelings/concerns/opinions without oppression and experiencing solidarity at times with my fellow carers/careworkers. The different ways opinions were expressed also helped me to evaluate how different people voiced similar opinions and ideas. The afternoon group didn't have quite such an impact but I still found the time valuable.'

'Organisation: the event was organised but there was a linked informality (you can be too organised!)'

'Monica cleverly asked only for words, not for the experience so you didn't feel quite so much as though you were sharing with a lot of people. Links between best day (wedding!) and worst day (also related to Mick) were very strong.'

'Allowing people to dump like that and think about the worst things, and then moving into the best (what are you most proud of?)'

What did you learn?

'I learned, at a personal level, to remember that I am a person first and a carer second and a professional third.'

‘I personally felt very flattered that my opinion counted so much that it was worth flying me down to London on about 10 seconds' notice to offer my contribution. ‘

‘It made the whole of the care agenda alive and real. I learned about the carer agenda context from the personal level to the policy level. The policy level came alive because the x million carers were represented in that room by real life personal stories.’

‘Now I find every opportunity to pass on what I’ve learned, tips and contacts. It’s just had a huge impact on me – professionally and personally.’

‘I had a real sense of people sparking off one another and putting new ideas together as a result of hearing one another's experiences, and out of that I hope a number of things that work for one set of carers can be made available to other carers, sharing 'best practice' if you like. I can't remember any of the specifics, but I do remember people at my table saying 'we do this', 'yeah, that would work, why can't we do that?', 'or if we did this, it would be even better!'

‘I have learned that my opinions are valid and often sought and that my wide experience of caring coupled with my own chronic illness has made me a valuable asset for the medical and associated world. Apart from my voluntary roles with our church my world had become rather insular….. I had forgotten that I used to be proactive and ready to take up arms in various ways. I had had a growing sense that I had the ability to be a voice for the voiceless, but felt incapable of taking on this role (mainly, I think, because of the depression I had suffered from and also because of my lack of self-esteem). The challenge of travelling to the conference, coping with the underground, finding a hotel (after losing the way ….) meeting all of you and acknowledging the company I was in certainly started to wake me up. As I have said before, I started the day unsure of myself and why I was there and left at the end of the day with a growing sense of my own sense of worth and responsibilities outside of my personal circumstances. I now have the confidence to challenge people (even healthcare professionals!) and their opinions/attitudes without being frightened of their reactions. Recently I even complained to the local and national BBC networks as a young lady was being portrayed and lauded as the best young carer in the South West, when in fact she was a paid employee of a nursing home. I don’t think the BBC will ever make the error of mistaking a careworker for a carer in the future!’

What could we do better?

‘I didn’t know the makeup of the participants in advance of the day. Would it have been helpful to have known this in advance? Because it was such a shock at a personal level, to realise that I had walked through the door as a professional but then engaged as a carer. Although I am a strong and focused person, it took a lot out of me to keep swapping hats during the day. Would it have been more ethical to know that I was potentially going to be exposed to participation as a carer? Or would I have prepared in a different way, so that what I contributed and gained might have been blocked? I'm not sure….'

'Provide more information before the day.'

'Allow more time for writing up post-its.'

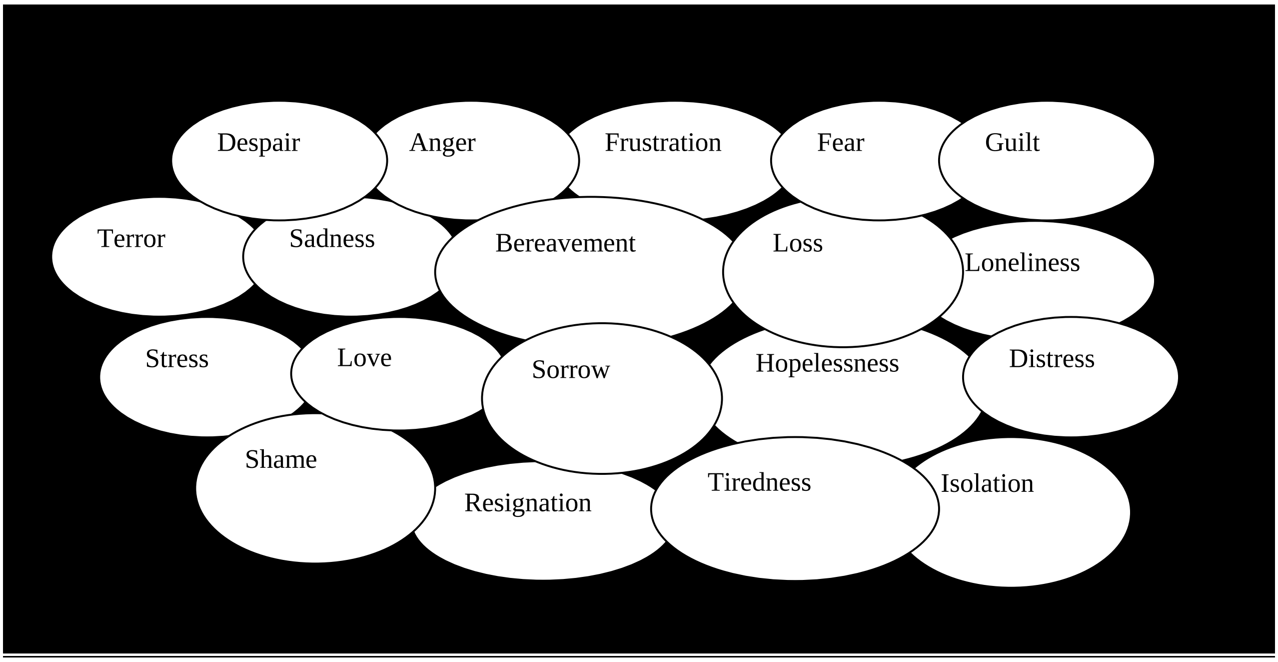
'Enlarge posters.'

'Provide better acoustics.'

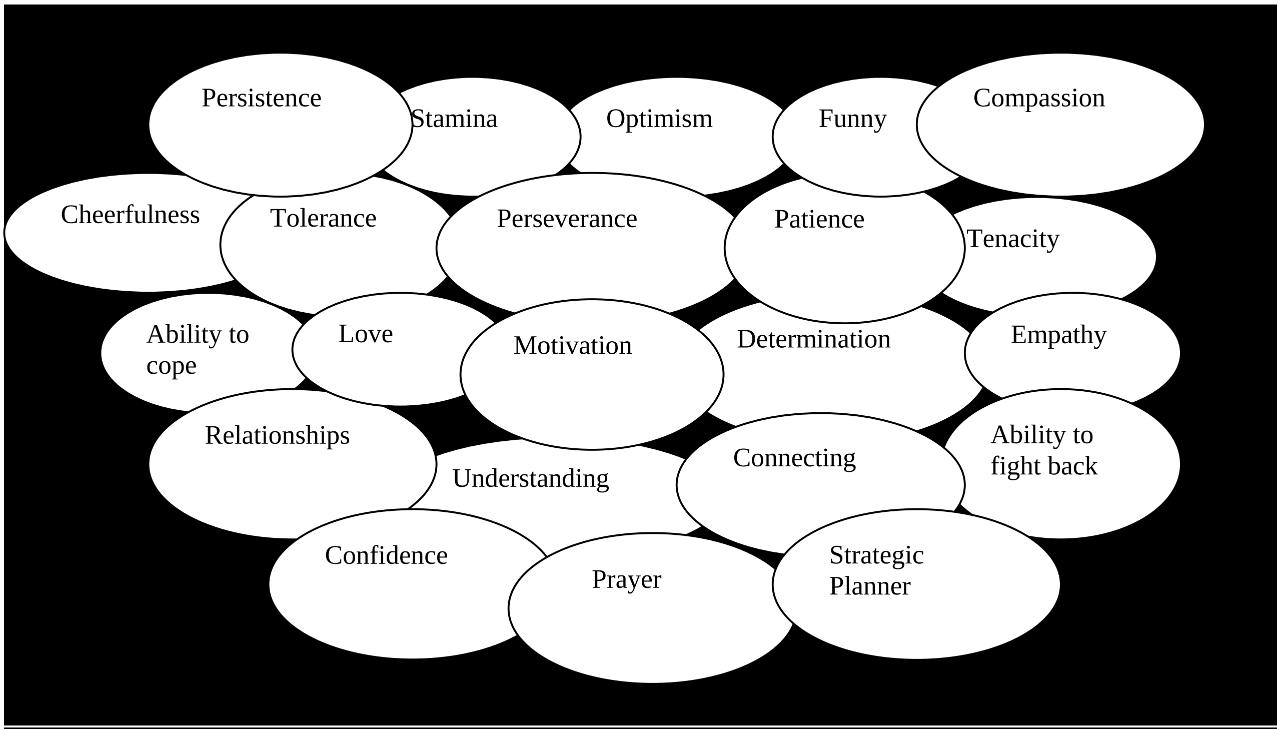
Appendix 3: Carers' feelings

Engaging Carers Workshop – 27th September 2004

The Feelings from Carers/Non Carers of their "WORST DAY"



The Feelings from Carers/Non Carers on "GOOD POINTS" of their own personality



Appendix 4: Summary of evaluation form responses

Engaging Carers workshop evaluation form

Monday 27th September 2004

Were you provided with enough information before the event?	Yes, Yes, thank you Couldn't open the flyer but enough to get me here Yes Only just. Draft programme seemed a bit "in-house" notes – would have liked a bit of advanced notice of what would be expected of me. Yes Yes Yes Yes Yes Yes Yes, my centre gave me
Why did you come to this event?	Curiosity, wanted to share experience and flattered to be asked Because it gave me an opportunity to try to make a difference Because I'm genuinely interested in Carers issues and want to find ways of keeping the profile high Invitation of Paul Stanton, interest in Carer involvement and impact of pain on Carers To push Carers' recognition forward. To make certain Carers views are expressed to NHS & Carers. Many times at PCT level Carers are not given that provision. A lot of PCTs will just consult with Carer's development Carers who in many cases act as "Gatekeepers" To share my experiences as a Carer and to listen to others I was asked, I wanted to be part of changing services Hope to improve recognition and support for Carers To try and influence the support given to Carers I was invited to attend via the Carer's Manager at the charity "Jewish Care" To meet Carers and enjoy the day
Did the workshop meet your expectations?	Yes Yes, but we could have done with more time to complete the writing-up of the tasks Yes – good to share experiences and look into peoples fears and passions Came with an open mind Yes it did – even better Surpassed what I expected Definitely! Yes, but wonder who was here and why? Yes Yes Yes Yes, very informative and helpful

What was the most valuable part of the day for you?	Seeing wealth of good ideas generated by group Meeting others with like minds, learning new information, seeing the whole picture Table exercises Meeting Carers – ideas – sharing Talking and sharing with other Carers Exchanged stories and workshops The group exercises Expressing views Informal discussion Hearing strong common messages – great minds think alike Exchanging information with other Carers Group discussion and the team – very interesting group
Did you feel that you had a chance to say everything that you wanted to say?	Yes Yes Yes Yes and perhaps more - had arrived with 'practitioner hat' on and participated as Carer There's not enough time in a day to do that – but it was fine Yes, very much so Yes Yes, but would have liked more opportunity to talk to other Carers Yes, well organised Yes Yes Yes
Is there anything else that you would like to add now?	Thanks for the opportunity! Need to emphasise that we Carers are human beings in our own right, aside from our role as Carers, we have a right to peruse our own hobbies etc – the need for that to be an essential, not a luxury, part of any care package Very well organised Very well run workshop – learnt a great deal about self and Carer agenda, media coverage – mentioned at end Would have liked more on how to discover invisible Carers No Will we get feedback? We (Carers) have the sympathy of Government/NHS/PCT and that's virtually all we have – very well organised, friendly event, many thanks to all those on the team. PS – thought – those 'heavy end' Carers without support could not attend. No No Another workshop like this

How could we have improved the day for you?	Better acoustics (split groups into different/quieter rooms) All was fine – good, tranquil venue I am a great one for networking and a little more info about participants I did not have time to talk to would be useful to enable contact post today. More dialogue with the professionals. They are the "invisible" ones – we never hear their point of view. Nothing – Best event of this type I have ever attended in years of being involved with the Carers movement It would have been interesting to know who people were, Carers, PCT staff etc, were any medical people there who were listening? Sound system was poor More updated information
What will you take away from today?	Determination to find out what's happening in Scotland! Lots of further points for campaigning The need to keep the Carers perspective in people's vision Ideas for practice - new friends and contacts Good messages – poss indigestion That all areas have similar probs Made some friends and contacts and realisation that so many others have the same ideas and issues That we are on the agenda and not forgotten Need for strong Carers voices, need to understand complexity of our situ Hope that the statutory authorities will provide more effective support for Carers The hope that the views of the Carers will be used to ensure that the Government recognises us fully. More confidence as a Carer

Note – 10 responses were from Carers – 2 from non-Carers

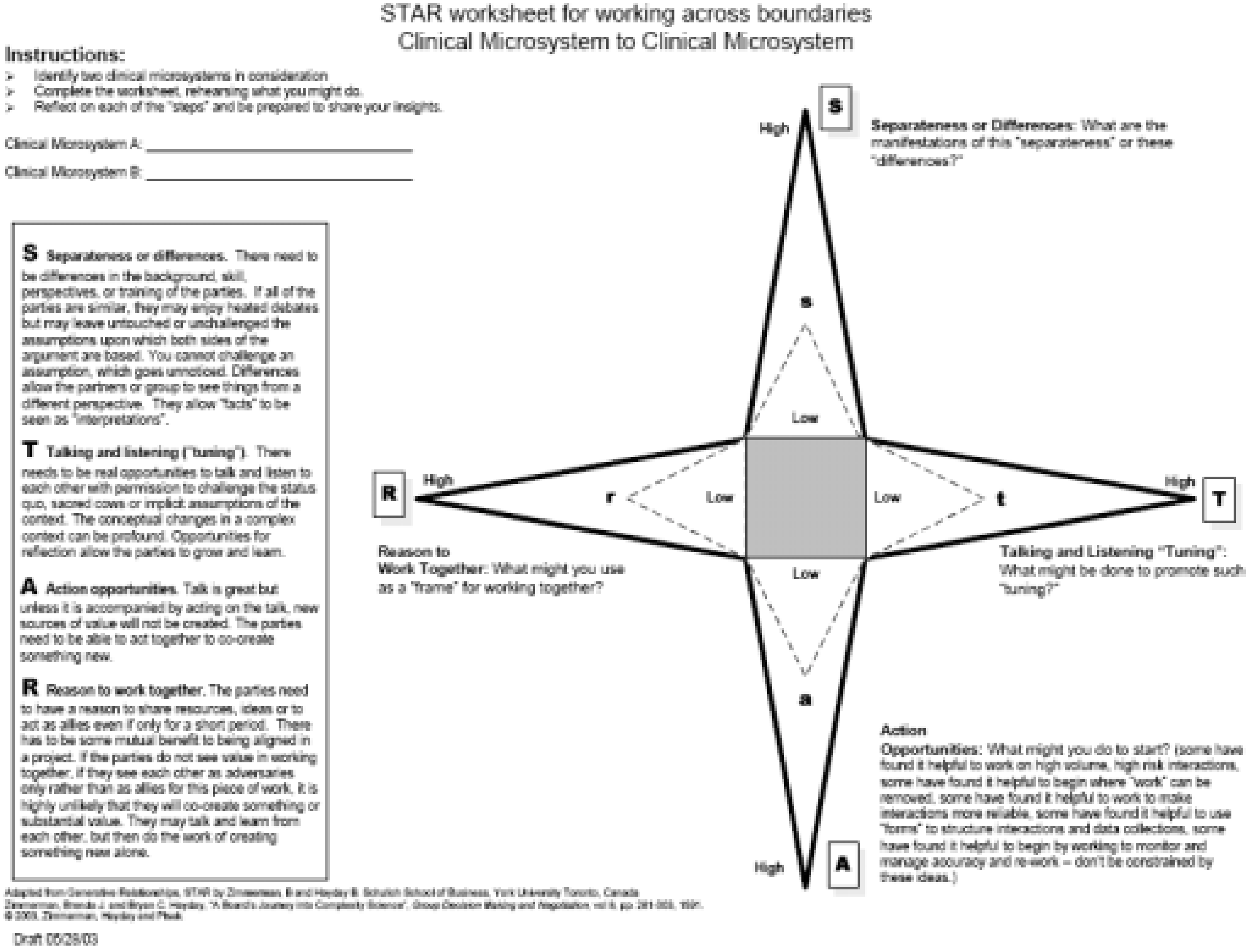
Appendix 5: Summary of organisers/facilitators' reflections on the day

- My colleagues are committed to new ways of engaging patients and carers. The old way was what I call the *consultation path.* On the *Consultation path* patients and carers are brought in as an "action" (as just another item on the entire action plan where it says "consult with patients and carers"). This time was different.
- The first thing the team did when the idea for the day was mooted, was to go to the carers' organisation to ask for them to help develop the idea. This meant that carers came onto the design team right from the start. This was a first for me.
- Everyone came to the day to give their whole. One very important element was the support and dedication of the admin team.
- All the planning was done in such a way that carers were treated completely equally with the rest of the participants – and were given the small extras which they needed to ensure that they could participate fully.
- Each of us on the design team took on particular jobs. One of mine was to liaise with the carers' organisation to ensure that the needs of the carers were fully met. This was accepted as non-negotiable by the whole team. What a difference this made from the old way of working! There was no need to spend time trying to convince people of the need for a budget for respite care and cash on the day, for example.
- New ways of working include the growth of the core team to include our external carer colleagues. Our mailing lists now include our new colleagues. We now exchange information about papers, seminars, discussions etc., freely with each other as team members do. Our team is committed to carrying on working in these new ways and I am so lucky to be a part of it.
- Truly collaborative working among the organizers, including a willingness to take risks with respect to the programme, and being prepared to deviate from the agenda.
- The willingness of those organising the event to be flexible towards the needs of the carers who attended, for example having cash for reimbursements available on the day.
- Good communication before the event, and where there was confusion, an open and relaxed attitude towards clarifying things;
- On the day – an open and friendly atmosphere where people felt that they were really being listened to and that the day had a point and would generate outcomes;
- The contrasting styles of the presenters helped make people feel at ease but also that this was a professional event where they were seriously being listened to and where what they said would have an impact on future work;

- The fact that there has been follow up work and the day obviously hasn't been forgotten is very valuable for all concerned and makes it more likely that any future event would be well attended and successful.
- From the start there was a passion from everyone involved.
- Monica's intense experience as a Carer provided and inspired a vision of what was needed from the event.
- We quickly established and continued with an excellent relationship between all the players Paul/Pip/Marion/Nicola (later on) Monica and Gerry, where ideas were welcomed and encouraged.
- We broke through the usual organizational, professional, cultural issues separating the health from the voluntary sector and were able to communicate at a deeper level. The event was both professional and human.
- There was clear leadership, aims and objectives and the realization that this was not simply a paper exercise but an event that would feed in to something greater and with meaning; not one which 'whispered in the wind.'
- There was a variety of expertise and talents, which complemented each other.
- There were excellent administrative and co-ordination skills; Marion and Nicola built good communication skills with each other – keeping each other regularly up-dated. The great potential for any confusion was therefore overcome.
- There was a clear focus on the needs of the carers who attended, for example having cash for reimbursements available on the day.
- The venue was great and gave attendees a sense of being important, valued. Importantly the food and drink was good.
- Carers and clinicians were greeted and welcomed warmly by all when they entered and by the organizers and facilitators. We were able to get into the swing pretty quickly and communication followed smoothly.
- The programme and structure were extremely well thought out and planned.
- There were clear action points and time-scales and a sense of follow through, even a sense of excitement about the possibilities for the future.
- There was an authenticity about the day, and attendees were able to engage both their hearts and minds, as well as believing that action would follow.
- In the first instance the organisers (Paul/Pip/Monica/Gerry/Nicola/Marion) all appear to posses a 'caring nature' themselves.

- There is a well-established and excellent business relationship between Paul/Pip/Marion and with Gerry/Nicola/Monica which helped in putting individual ideas and their voices forward.
- The venue was a trusted one – having held many workshops there previously which helped with knowing who to ask for further refreshments/photocopying etc on the day.
- I feel Monica's experience as a Carer helped tremendously to see for 'real' what being a carer is all about. I realise everyone else probably has experience too but through the patient stories and Monica's openness about her past, her experience and emotions came out.
- Pip/Paul/Monica had an excellent ability to look at what was needed in the overall picture with input from Gerry on how the feel for the day should be.
- Marion and Nicola built good communication skills with each other – constantly informing each other of potential attendees and contact details.
- Pip and Marion kept in touch by phone and email updating each other on their views.
- There was confusion at times with who was doing what but that soon got ironed out by picking up the telephone to confirm.
- Having someone to help greet the Carers & Clinicians made a difference in that people felt they were welcome and the day appeared structured and well planned out. Pip suggested Marion attend and Nicola also attended which made the administration of the day go efficiently.
- I feel the Carers & Clinicians did feel welcome and were able to talk quite freely amongst themselves in their sessions – aided by the layout of the room in 'cabaret style' – which I feel seems the most effective way of working in a facilitated event.
- Paul, Monica and Gerry all came across well in their facilitation to the group not only because of their good facilitation skills but because of their real enthusiasm to the cause.
- Paul's broad knowledge on the NHS and his ability to capture the audience – came out well again.
- Brendan's ability to work well and capture what the groups were saying came across.
- The 'proof is in the pudding' as they say and looking through the Evaluation Sheets showed that everyone who replied felt the day was very worthwhile and rewarding. The Carers all commented that they had chance to voice their feelings and they got a sense that at least someone else understands how the Carers really feel.

Appendix 6 The Generative Star



STAR worksheet for working across boundaries
Clinical Microsystem to Clinical Microsystem

Instructions:

- Identify two clinical microsystems in consideration
- Complete the worksheet, rehearsing what you might do.
- Reflect on each of the "steps" and be prepared to share your insights.

Clinical Microsystem A: ______________________________

Clinical Microsystem B: ______________________________

S **Separateness or differences.** There need to be differences in the background, skill, perspectives, or training of the parties. If all of the parties are similar, they may enjoy heated debates but may leave untouched or unchallenged the assumptions upon which both sides of the argument are based. You cannot challenge an assumption, which goes unnoticed. Differences allow the partners or group to see things from a different perspective. They allow "facts" to be seen as "interpretations".

T **Talking and listening ("tuning").** There needs to be real opportunities to talk and listen to each other with permission to challenge the status quo, sacred cows or implicit assumptions of the context. The conceptual changes in a complex context can be profound. Opportunities for reflection allow the parties to grow and learn.

A **Action opportunities.** Talk is great but unless it is accompanied by acting on the talk, new sources of value will not be created. The parties need to be able to act together to co-create something new.

R **Reason to work together.** The parties need to have a reason to share resources, ideas or to act as allies even if only for a short period. There has to be some mutual benefit to being aligned in a project. If the parties do not see value in working together, if they see each other as adversaries only rather than as allies for this piece of work, it is highly unlikely that they will co-create something or substantial value. They may talk and learn from each other, but then do the work of creating something new alone.

Separateness or Differences: What are the manifestations of this "separateness" or these "differences?"

Reason to Work Together: What might you use as a "frame" for working together?

Talking and Listening "Tuning": What might be done to promote such "tuning?"

Action Opportunities: What might you do to start? (some have found it helpful to work on high volume, high risk interactions, some have found it helpful to begin where "work" can be removed, some have found it helpful to work to make interactions more reliable, some have found it helpful to use "forms" to structure interactions and data collections, some have found it helpful to begin by working to monitor and manage accuracy and re-work – don't be constrained by these ideas.)

Adapted from Generative Relationships, STAR by Zimmerman, B and Hayday B. Schulich School of Business, York University Toronto, Canada.
Zimmerman, Brenda J. and Bryan C. Hayday, "A Board's Journey into Complexity Science", *Group Decision Making and Negotiation*, vol 8, pp. 281-303, 1999.
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