

# **Innovation in Hospice and Palliative Care**



## **Report of a workshop**

**Held on 3<sup>rd</sup> December 2004**

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# **Innovation in Hospice and Palliative Care**

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## **Innovation in Hospice and Palliative Care**

*Acknowledgement.*

*Help the Hospices would like to thank the organising group:*

Steve Kirk, Chief Executive, St Lukes Hospice,  
Terry Magee, Director of Education, St Helena's Hospice,  
Jane Mason, Chair, Quality and Standards Group,  
Barbara Monroe, Chief Executive, St Christopher's Hospice,  
Raymond Dempsey, Independent Consultant

And in particular all the contributors on the day

## **Innovation in Hospice and Palliative Care**

The Chair's for the day was Jane Mason. Jane Mason is a Trustee of Help the Hospices, Head of Nursing at St Michael's Hospice and Chair of the IHRC Quality and Standards Group.

### **1 The Challenge of Innovation**

#### **Steve Kirk, Chief Executive, St Luke's Hospice, Sheffield**

'What is hospice care' produced by H.I.S in 2004 states that Hospice Care 'is regarded by some as one of the greatest social innovations of the last hundred years.'

Innovation is linked to change but change has different meanings for different people. Whilst some see change as difficult, challenging, uncomfortable and threatening, others see change as new, exciting and beneficial.

An example of innovation within the hospice movement is demonstrated by an idea at St Gemma's Hospice to deliver a patient centred meal service. This changed the whole institutionalised way of providing meals to patients. A patient could order any meal at any time and it would be with them within 20 minutes. This was hard to implement. Staff didn't want to change what they normally did as it suited them. Everything had to be changed, including staff rotas, which had traditionally been drawn up around the old meal times. This was a challenge to the hospice but it focused on the needs of the patient. When the meal service was up and running staff forgot about all the hard work that had been involved in making it happen.

#### **Hospices – Why can they be Innovative?**

- Perceived fewer constraints than the NHS
- Quicker timeline from idea to action
- Immediate effect and feedback
- Independent feedback through volunteers. Volunteers will give direct and honest feedback as they have nothing to lose through being honest.
- Supporters see the good ideas and want to invest. If they can see that patients are seeing a direct benefit then they will want to invest more in the hospice
- Staff choose to work there. Hospitals tend to have more staff in training posts and working in areas that are not their particular area of interest. Staff within a hospice have taken the specific opportunity to go and work there.
- Ethos. Staff within a Hospice are supportive of innovation.

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### **Hospices – Why are some not so innovative**

- Stuck in the past
- Staff, trustees and volunteers stuck in their ways
- Don't want to change – too challenging. Staff like what they do and the way it is done.
- Funding. Hospices are often limited by funding. Good ideas often cost money.
- Leadership. Trustees and Chief executives need to accept ideas and be supportive of ideas and innovation and help to foster a culture of innovation within the hospice.
- Motivation. Need to keep motivated even in the face of adversity.

### **Innovation**

- Innovative – to bring in new methods, make changes
- Why innovation/change?
- Think of Hoover (1912) and Dyson (1983)
- Day hospice and community services. Hospice could re-look at this and see what they could be doing differently so that people use it more/buy in to it more. Maybe change the way the service is presented?
- One's current practice is someone else's innovation. Listen to other hospices innovation and think about how that can be applied within your hospice.

### **Hospice Innovation – What's Next?**

- Spiritual Care centres
- Hospice v Specialist Palliative Care Centres
- Day Hospice v Creative Living v Therapy Centres
- Respite v interval admissions v supportive care
- Macmillan nurse v specialist palliative care nurse
- Is there anything left to innovate?

### **Ingredients for Innovation**

- Errors
- Ideas. Ask patients and volunteers for ideas
- Intelligence. The right people with the right mental skills and attitude are needed.
- Investigation. Research has to be carried out and then scrutinised.
- Opportunity

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### **Innovations?**

- Would you be surprised if this patient died in the next year? This question was asked to physicians in America. If the physician answered yes, they were not allowed to see the patient.
- Advanced Directive Education
- Respite! Should it be reinvented or re-stated?
- When is end of life care? The last 6 weeks, 6 months or 6 years of a person's life? At what point do hospices get involved?

### **Innovations in Palliative Care – Research and Practice – 2005**

- Measuring individual quality of life with SEIQoL –DW on hospice admission: is it any use to nursing staff?
- The German version of the palliative care outcome scale (POS)
- Where the oldest die from cancer – what does this mean for specialist palliative care providers
- How is spiritual care at the end of life understood and provided in the UK?
- COPD, Respiratory Nurses and Palliative Care
- Bereaved grandparents 'experiences of losing grandchildren to primary central nervous system tumours.
- Evaluation of an ethics history for hospice in patients to facilitate information and decision making
- Assessing the quality of informed consent given to patients in palliative care research trials.
- Attitudes of local research ethics committees to research in palliative care.

*As the births of living creatures at first are all ill shapen, so are all innovations, which are all births of time* Francis Bacon 1561 – 1626

## **Innovation in Hospice and Palliative Care**

### **2 Learning from others – presentation sessions**

#### **2a The Development of CD rom to complement and enhance current syringe driver training**

##### **Jo Wells, Princess Alice Hospice**

Education on the use of syringe drivers was being provided to nurses in hospices, community and hospital settings on a yearly basis. Princess Alice Hospice looked at how they might provide ongoing training more frequently for their nurses.

Between 1990 and 2000 there were 1495 adverse incidents involving infusion pumps. MDA (2003). These were a result of misleading admin set, misleading syringe, setting at the wrong rate, confusing pump type and configuration of the pump. There is a high incidence of human error and a need to re-evaluate the existing training

Nurses reported

- Confusion over two different types
- No consensus of how to set up
- Loose confidence as infrequent use
- Forget how to set up
- Concern over compatibility of drugs
- Not having access to updates
- Not having equipment available.

The Educational literature shows

- Traditional teaching methods could not ensure a consistent approach to teaching skills and accommodate diverse learning styles (Jefferies 2000)
- If students are required to interact with the material they are learning, they become active participants instead passive bodies (Elliott 1996)
- Students learn more if they see, hear and interact with the learning process (Elliott 1996)
- Using traditional and interactive methods together produces achievement effects superior to those of one method alone (Jefferies 2000)

The hospice planned to produce an interactive package that was informative and took into account some of the previous findings. Most importantly the package had to be fun to use.

The first step was to try to seek funding for the computer software, equipment and training. A grant application was submitted to the Janet Squire Bursary and £2395 as awarded for the project.

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### What happened next?

- The IT department decided that they could not continue. Therefore more money was needed to complete the project.
- The two cancer networks the hospice is part of set up syringe driver steering groups.
- They became interested in working collaboratively to disseminate the CD-Rom to a wider audience.

### Progress to date

- The hospice put together a proposal to the networks for funding and this was agreed.
- A questionnaire was sent to all group members asking what content they wanted.
- Three quotes were obtained from production companies and choice of company was made.

The Princess Alice Hospice now hopes to finish the CD Rom package and the use it to supplement existing training. The next step would then be to evaluate its effectiveness in the clinical areas and to publicise it.

### Problems and Solutions

#### Problems

Funding

IT department unable to  
Produce the CD Rom

Time delays

#### Solutions

Initially a grant  
Cancer network

finding an appropriate  
production company

Patience  
Set realistic deadlines and be flexible.

## 2b Creative Living? The future of specialist palliative day care Nigel Hartley and Rebecca Bennett, St Christopher's Hospice

The creative living centre at St Christopher's Hospice provides psychosocial and spiritual care to all departments at St Christopher's hospice. As well as being available to individual patients and groups of patients within the Day Unit facility, the Creative Living Centre also offers Creative and complementary resources to



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patients and their carers who have access to the hospice via the Home Care Team and the inpatient wards. The centre also forges links with related projects in the local community. Through offering information, educational and support, the Centre seeks to enable people to discover their own strengths and resources during advanced disease and to provide healthier attitudes towards death and dying.

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The service St Christopher's offer includes:

- Craft work
- Art work and painting
- Art therapy
- Artists with computer/digital skills
- Music
- Music therapy
- Gardening
- Acupuncture
- Horticultural Therapy
- Reminiscence
- Hypnotherapy
- Aromatherapy
- Reflexology
- Massage
- Pottery/ceramics
- Creative writing
- Hairdressing

St Christopher's carried out a 'Quick and dirty' survey and found that people attended day care to meet people in the same boat, for respite from/for family and carers and for introduction to the context of a hospice and feeling safe.

*'I only attend for the counselling...I've tried relaxation and I can't do that...Not really interested in art and craft...I have come all day just for the counselling...'*

*'They're like my own people, no matter how you are down, if you are ill, or if you are weak, they make you strong. Everything you think of it's to give you life, and I can say that ever since I've been coming I feel that I'm not sick, I'm not ill – I am ill – but I feel like there's nothing wrong with me.'*

Not one of the creative or complementary therapies was mentioned in the patient survey. If the patients are not attending for the therapeutic/creative activities, then what should be done at Day Care and why? This was worrying for the team as this had been provided for years.

Hospice Day Care is currently facing a number of challenges

- Moving from protest to partnership
- Stronger relationship between NHS and voluntary sector
- Introduction of NICE and PCT networks
- Competition for funding of care and supply of care
- Need and demand for equity of care and choice of resources
- Need for responsible and dependable evidence base

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The challenges that are faced in smaller departments within hospices are important because they cut through the whole organisation and systems that have been in place for many years.

### **What will the new Specialist Palliative Day Care look like?**

The NICE Guidance on Supportive and Palliative Care states that there is insufficient evidence to support adoption of any particular model of day care and issues of access need to be addressed.

The vision of the Creative living centre is that all these services should be offered to every patient, carer, and family member and not just for day care. It should be available out in the community.

This leaves us with a number of questions to address

- What kind of projects do we need?
- What kind of funding will it be
- Where will work take place?
- What about Day Care? What is day care?
- What should the core team consist of – this will be determined by the changing future and what we know will happen.
- What does the specialist palliative care day nurse look like
- Access to day care – who? When? Where? – there is a huge need in the community that is not currently being met. Is day Care defined by the building it is in?
- Referral/Discharge/evaluation? If don't know why people are coming what objective should be set and how does the team meet their needs?
- What are the internal and external interfaces
- How do we manage internal and external interfaces
- What will be the impact on holistic care – in all settings?
- How can we audit the impact of the changes?
- Once outside of our own systems – how do we decide who receives it?

### **Our Future**

As the third generation of palliative care providers we don't have to do what was done 50 years ago. This will be enormously challenging but the challenge and innovation is exciting.

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### **2c Exploring the Perception of Breaking Bad News: A working poster**

**Debbie Smithers, St Michael's Hospice**

The aims and objectives of the project were to provide a flexible and educational resource, to highlight key issues for patients and the professional, to promote discussion, to enhance existing knowledge and to provide an abstract format that promotes safety for users.

The poster can be used in small workshops and in discussion groups. The character pictures can be interchanged and a selection of posters can be used along with picture cards.

#### **Methodology**

- Explore key themes – cultural issues, psychosocial issues
- Sub divide the group
- Set specific tasks
- Compare and contrast responses
- Explore identified learning needs.

#### **Evaluation**

The poster proved to be a useful and in-expensive teaching resource. It was practical and user friendly and helped to promote discussion and raise awareness. The poster also helped to reinforce existing knowledge.

However, the initial production time for producing the poster is quite time consuming and gaining access to pictures can be time consuming. The issue of anonymity and the inability to confirm perceptions of the pictures is a problem.

St Michael's plans to increase the usage of the poster in the future.

### **2d Development of a Discharge Care Pathway**

**Vivienne Forrester and Gillian Edgerton, St Giles Hospice**

The aim of the project was to develop an integrated core pathway involving all appropriate healthcare professionals to achieve a seamless and timely discharge. The patients and carers needs will be central throughout this process.

An audit was carried out of the long term stay of patients. This brought up lots of points and recommendations. It also showed that there were no services within social services to deal with discharges. There wasn't the man power or equipment. People from the Primary Care teams, district nurses, continuing health care professional and social workers were invited to look at new ways of

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working. This started off with a brain storming exercise. People were then sub divided in to three different interest groups with one group looking at the Delayed Discharges Act and continuing health care , one group looking at the pre admission screening tool and the final group looking at the diversity of the care pathway.

All patients expressing a wish to go home will be put on the Discharge Care Pathway. Labels are issued once the patient has been accepted for care at the hospice and the pre-admission checklist is completed before admission. A named nurse will be identified and will discuss discharge with the patient and family within two working days of admission. On the same day the nurse will contact the Primary Care Team and the patient will be assessed within two working days. A case conference will be arranged if appropriate within two working days and a response from all invited within 24 hours.

A care package is set up within 5 working days of contact and equipment will be ordered and delivered within 3 working days. If any deadlines have not been met these will be discussed at the next multi disciplinary team meeting. Transport is arranged 2 working days before discharge and medication is prescribed and ordered 2 working days before discharge.

### **Development**

- Process mapping exercise – Admission to discharge
- Review of process map by all hospice departments. Talk about discharge of a patient before admission or within the first 48 hours.
- Set standards.
- Review of standards by all health care professionals and social services,
- Development of documentation

### **Implementation**

- Education
- Question and answer sessions
- Display of pathway with opportunity to comment
- Support from two staff nurses and OT.
- Introduction of care pathway March 2004
- Re-enforcement and support
- Documentation audit June 2004. This showed that maybe it had been implemented too soon and was a little too ambitious. The pathway was not being used in ways in was meant to be used.
- Feedback and amend. A discharge liaison nurse is now in post.

### **Future**

- Monitoring

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- Patient and carer satisfaction survey
- Health Care Professional Satisfaction survey (including community and social services)
- Re-audit of long stay patients 2005.

### **2e Course for carers**

#### **Jenny Newberry, Dorothy House Hospice**

As part of the Bereavement Service offered at Dorothy House Hospice the hospice offers an assessment visit to the next of kin at 4 – 6 weeks after death.

The idea from this project came from one of these visits to a bereaved husband who had cared for his wife with breast cancer until her death at home. He felt that he would have liked a course to prepare him for the role of carer. Canvassing other carers and bereaved relatives suggested that there was a demand for a course for carers.

The idea for a course was taken to the full team of community nurse specialists and agreed in principle.

The innovation was to develop and deliver a short course for carers by four community palliative care nurse specialists. Approval was sought from the hospice's multi-disciplinary Joint Development Group and evaluation was built in from the outset. The hospice worked in partnership with carers and involved them in what they wanted from a course for carers. The district nurse, a hospital dietician and a complementary therapist were also involved in the teaching team.

The aims of the course were to provide practical information and advice, explore the emotional impact of illness, to offer support and to help the carers to look after themselves so that they can look after others.

#### **Course Programme**

- Week 1 Accessing information and support
- Week 2 Understanding illness and treatment
- Week 3 Practical hints and tips
- Week 4 If the worst comes to the worst
- Week 5 Looking after yourself

Critical success factors can be found in quotes from patients who attended the course

'Really informative about what to look for at the end and how to cope'

'The strength to carry on knowing you are not alone'

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'Understanding you are not unique in your sometimes negative feelings and not to be ashamed of them'

'Helped in all ways to cope both with the patient and oneself'

The project worked because the whole organisation was brought on board from the beginning, the course had set aims and outcomes but at the same time responded to the group's needs and pace.

The hospices intendeds to keep the momentum going and aims to repeat the course twice a year involving other members of the team.

### **2f Service User Forum**

#### **Anna Wolkowski, Janet Dean and Bill Chappell, Dove House Hospice**

The idea for the Service User Forum came from a genuine desire on the part of Dove House to consult and involve service users in the development and evaluation of services. The Chairman and Chief Executive were highly committed to principles of service user involvement .The group was encouraged by the NICE guidelines on supportive and palliative care. The head of nursing was asked to take the lead on the project.

#### **The motivation to develop a service user forum**

- A wish to involve people who use services provided by Dove House Hospice in looking at how these services can best be improved and developed.
- A wish to give people the opportunity to fee; part of the Dove House Service. Give them chance to use their skills and knowledge to help the hospice develop
- A wish to balance power between people who use a service and professionals who provide a service through Dove House Hospice

The purpose of the forum was to try to provide the opportunity for maximum involvement of users and carers in developing an appropriate responsive specialist palliative care service.

#### **The key principles of the forum were**

- The meeting would be approximately every two months in a comfortable room in the hospice
- There is an open invitation to all users and carers by publicity and word of mouth

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- Transport is positively offered
- The day of the meeting to be changed in sequence to allow maximum accessibility
- The timing is agreed with service users and the best time for them e.g.: Morning – middle of the day
- Refreshments and lunch are provided
- A familiar nurse is always available to attend users nursing needs
- In order to encourage openness, staff who are in a management position at the hospice e.g. Head of Nursing, do not attend.

The service user Forum feedback meeting was set up as a mechanism for ensuring that issues raised in the forum would be listened to properly and taken seriously.

### **Achievements of the forum so far include**

- New name badges for all staff (ones that patients can easily read)
- A patient run library
- A suggestion box
- Badges for patients (all the forum's idea and available to any patient who wants one)
- Horticulture groups
- A review of physiotherapy services
- A review of transport provided for day therapy patients
- Fire procedure on care plan
- Disabled parking improved
- Patient led discussion groups

### **Do's – for setting up a service user forum**

- Show a genuine interest and listen to what users have to say
- Set agenda for the day and prioritise items for discussion
- Perseverance and support

### **Don'ts**

- Drift from meeting to meeting with no feedback
- Fail to deliver on action proposed
- Use 'university talk'

Dove House are now looking at devising other forums to gain feedback and new ideas from other client groups who access services e.g. bereaved relatives



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### **3 Innovation in local service settings- the case of day care**

One service was chosen to discuss in detail - Nigel Hartley and Rebecca Bennett, St Christopher's Hospice were chosen to lead the discussion.

Nigel and Rebecca led a discussion on the challenges facing Day Care services.

When looking at Day Care services, objectives have to be considered. When all the creative activities are taken away why do people still come? There is something very special about day care that is not acknowledged or evaluated. People do not want to leave the service. People start to feel like it's their home and family and it becomes so vital to them that they don't want to leave. Until hospices can define what day care is and what it is doing then hospices are not going to receive funding for it.

With such a small number of patients accessing day care, why can't psychosocial and spiritual care be given in their own homes. When people become ill to attend day care all these things are taken away from patients. Patients living with a terminal illness are really isolated in society and the crucial value of day care mustn't be lost. Hospices need to think about a plan of leave as well. There needs to be a plan of long term care in place to meet patient's long term social needs. There needs to be a clear contract of expectation and what the service is offering. This needs to be tailored to each individual's needs rather than just one package to fit all.

This discussion is a reflection of the debates and challenges that day care services are facing. Issues around equity also need to be addressed. Patient populations are changing and hospices may not be responding appropriately.

The possibility of setting up a national working party to look what a new day care would look like was suggested

### **4 Telemedicine in community based palliative care Emma Saysell, St David's Foundation Hospice Care**

A national shortage of consultants in palliative medicine in the UK led St David's Foundation Hospice Care to begin an innovative telemedicine project in October

Each week the CNS hold a teleconference with a consultant in palliative medicine. The consultant is only paid for the hour of the teleconference. The role of the teleconference time is structured and targeted.

The use of telemedicine is explained to all patients before their case is discussed and permission is obtained. Patient confidentiality is maintained and no personal

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identifiers are used. All patients discussed also have the verbal consent of their GP.

A number of criteria were developed which have to be satisfied for a case to be discussed. Patients are required to have one or more unresolved symptoms that have already been discussed with the primary health care team and have remained unresolved.

GPs are encouraged to attend but many are unable to because of other time commitments. The CNS and the consultants discuss the problem and the CNS gives feedback to the GP, The GP then decides whether to act on the advice given and the outcome is documented.

Discussion also takes place around day to day practice that raises issues which are important to review, so that skills and expertise are enhanced. General palliative care topics, including ethical issues, alternative treatments and psychological problems are discussed at specific education sessions.

All sessions are recorded, videotaped and the tapes are stored in a locked cupboard. This ensures that the advice and relevant information is available should the GP require classification, and to satisfy clinical governance policies. The CNS are also then able to refer back to the advice given. GPs can view the tape if they wish. The sessions are also used on study days at St David's.

After each teleconference the participants are asked to complete a number of questionnaires and monitoring forms.

St David's are hoping to develop a project where telemedicine can be taken in to people homes, establish additional teleconferencing sites and continue to develop the evidence base for telemedicine to enable future expansion.

## **5 Reflection by Andrew Webster – Innovation Health Technology (IHT) Programme**

### **The IHT Programme**

- 30 projects and 145 researches
- £5m 2000 – 2005 funded by the medical research council
- Technology focus: genetics, ICTs, assistive technologies and devices, imaging, novel drugs
- Main themes: risk, identity, governance, innovation, social management of health, social inclusion/exclusion
- Question: how will people and society be affected in turn affect IHTs?

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## **Innovation means**

- Existing expectations and practices disturbed
- Novel functionality
- New production, new markets, new regulation
- Novel organisational demands
- New skills/knowledge demands redefined
- Social and biological boundaries redefined

## **Summary of portfolio of results**

- Risk, it's measurement and calculation e.g. the precision and accuracy of medical diagnosis; the needs for context- informed, patient centred algorithms for care
- Innovation itself – and the development of new methodologies for tracking this and determining the dynamic relation between design, use and regulatory contexts
- Patient 'narratives' narrative in a number of fields and how mediated by technology
- New sustentative studies in a number of areas – such as PiGD, telemedicine, xenotransplantation, NHS Direct etc
- Analysis of the ICT/information nexus and its role in shaping illness, symptoms, health delivery/support
- The relationship between context of use and the implications this has on formal metrics of evaluation
- The regulatory arenas within which IHTs are located – new drugs, biotech, tissue engineering etc.

## **Key issues for successful innovation**

- Greater technical interdependency – need to understand interlinkages across innovation fields
- What generic and field specific obstacles to innovation can be identified?
- Are distinct patterns of innovation emerging as a result of the problems medical science seeks to address?
- How will innovations (in any technical area) tie in with 'integrated care pathways' of patients?

## **Implications of IHT programme for medical innovation**

- Need to strengthen our understanding of the relationship between new technologies, context of use and interpretation
- What is the impact of new technologies on 'integrated care pathways' – implications for NHS SDO guidelines?

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- Need to strengthen role of qualitative research in evaluation of interventions
- Role of patient in innovation and assessment new technologies is important

### **Raising standards, innovation and Partnership: how and where?**

Broadening and redefining the focus and range of hospice care – (in the community, creative arts, complementary care etc); do pain relief technologies ‘travel’ equally well – from a day hospice to a home setting?

Carers and technologies: palliative care in the home – managing new routines, use of new techniques (e.g. dermal patches)

Further details about the IHT programme can be found at [www.york.ac.uk/res/ihp](http://www.york.ac.uk/res/ihp)

## **6 How we can work together to improve practice across the country**

### **Barbara Monroe, St Christopher’s Hospice**

If hospices share good practice the people who innovate need the ownership of that as this can be linked to funding and profile. Different approaches are needed as well as keeping things rolling and disseminating good practice

There are a number of big questions. How are we going to share ideas about the big questions?

### **What could Help the Hospices do to help innovation?**

- Professional writer – Help the Hospices could employ a professional writer to attend a brain storming session and write up the ideas. This would have to have to be a fast idea to print turn around. The final publication would need to have the names and logo of all the organisations that contributed to the report.
- Training events
- Funding rounds for innovations – 2 stands of funding with small and larger grants being made available to hospices.
- The formation of a National Working Group – Society is changing and hospices need to address how best to deal with this