

Hospice UK stakeholder meeting

Dr Sarah Russell, Head of research and clinical innovation at Hospice UK, reports on 'Research Ready and Active Hospices'



Research activity enables hospices to provide the best possible care, understand which interventions make the most difference as well as contribute to the national and international body of knowledge. Princess Alice Hospice is a good example of the combination of research and practice in the provision of evidence and compassionate care.

In 2010, the think tank Demos published a report entitled 'Dying for Change' which highlighted some of the challenges facing hospices in the future. Help the Hospices (Hospice UK) responded to this report by setting up the Commission into the Future of Hospice Care to provide guidance, information and options for hospices to inform their strategic position and offerings in the next 10 to 20 years.

One of the reports to be published as part of the work of the Commission made specific recommendations to support hospices to be research active – a research active hospices framework. In the period 2013-2016, many hospices took forward the framework individually or in local groups. However, there had been no repeat mapping or consultation with all the hospices since the publication of the Commission report. Therefore, from November 2015 to June 2016 a stakeholder consultation took place of over 200 people in a variety of roles from hospices, universities, NHS research, NHS clinical care, governing bodies, interested parties and national leaders. The aim of the consultation was twofold. To ensure we knew what we thought we knew about the research readiness or activity of hospices and to be a collaborative platform to direct the future actions of Hospice UK, based on the needs and experiences of the hospice community.

What did the consultation tell us?

There is a call for hospices to contribute to the body of research knowledge.

There is an appetite for hospices to be research ready and active but a lack of confidence or capacity in some areas in taking it forward. More work is needed to increase the research readiness and capacity of hospices to be research active, engaged, generating or leading.

Research ready refers to a hospice being ready for research activity

Research activity refers to hospices being research active, engaged, generating or leading.

Research Active (all)	Research Engaged (many)	Research Generating (some)	Research Leading (few)
'Staff and hospice is a critical consumer of research'	'Staff and hospice engage or contribute to research done by others'	'Staff and hospice actively undertake and generate research'	'Staff and hospice lead research activity'

There is a desire to set up consistent internal research governance and reporting systems for hospices, to define and map research readiness and activity, understand education needs, seek funding streams, address organisational culture and capacity issues as well as relationships with universities, the National Institute for Health Research (NIHR), Clinical Research Network (CRN) and other key stakeholders.

There is a need to provide clarity about indemnity, NHS site status (variability across the country in how this is interpreted) and how that operates, as well as organised networking (with a centralised access point) including ideas, peer support, research leadership, sharing of resources and education pathway. Concerns about funding and how hospices can carry out research within the NIHR portfolio is also present.

There is a curiosity about if to accredit in some way research ready and active hospices with a preliminary objective that patients and families understand what research active/ready hospice means to them.

There is an appetite for Hospice UK to play a central role in knowledge exchange and networks of learning or, in other words, organised networking which enables the sharing of knowledge and experiences, peer support and influencing as well as collaboration with others (e.g. NHS, academic and hospices).

Next steps?

1. Establish a 'thought leadership' group to advise on the strategic direction for research ready and active hospices.
2. Develop 'real world practice' advisory groups to advise on content, relevance and practicalities in the key areas of:
 - a. Clarification of the operationalisation of research active, engaged, generating and leading
 - b. Share models of regional hubs and peer networks
 - c. Define relationships with academic centres and Universities
 - d. Identify workforce development needs and solutions
 - e. Provide position statements on areas such as hospice as non-NHS sites and indemnity issues
 - f. Map research readiness and activity
 - g. Implement an interactive platform for the sharing of resources, ideas, experiences.
 - h. Produce resources, position statements, products and case studies which enable hospice research community to develop and sustain their activity
 - i. Engage and collaborate with stakeholder community for mutual benefit.

So how is this activity relevant to Princess Alice Hospice?

In a nutshell, Princess Alice Hospice has been a major contributor to the stakeholder consultation process as well as a leading example of a hospice that is generating relevant and influential research.

Research activity at Princess Alice Hospice

The Prognosis in Palliative care Study II (PiPS2)

Professor Paddy Stone, Marie Curie Palliative Care Research Department, University College London.

Hospice Detection Deep Vein Thrombosis Study (HIDDEN)

Professor Miriam Johnson, University of Hull Medical School

What services influence the care of people with dementia in the last year of life?

Dr Jennifer Todd, Princess Alice Hospice

Development of an educative intervention for nurses working in palliative care to enhance their confidence and competence in communicating with parents and children when a parent nears end of life.

Professor Emma Ream (doctoral study of Penny Franklin), a partnership between University of Surrey and Princess Alice Hospice

Can a palliative care education intervention improve and sustain participants' confidence and professional development in palliative care and does this translate to care delivery?

Dr Jennifer Todd, Princess Alice Hospice

LEGACY (Rapid Medical Donation Programme for Breast Cancer)

Peter Barry, Royal Marsden Hospital

The influence of Intercultural Communication in discussion of Advance Care Planning: The case of nurses and care home residents in the UK

Jane Berg (doctoral study), Head of Education, Princess Alice Hospice

The Use of Bibliotherapy in Supporting Bereaved Children: A Publishing Perspective

Elle Waddington, MA Publishing Kingston University

Supporting cancer patients with an intellectual disability.

Samantha Flynn, Doctoral Student, University of Chester

The experience of counsellors working with clients at the end of life.

Patricia Mooney, BA (hons) student, Middlesex University

Hospice UK conference 2016: key messages

Professor [David Clark](#), School of Interdisciplinary Studies at the University of Glasgow, opened the Hospice UK conference with a sweeping history of end of life care from the nineteenth century to present day. He categorised the chronological development of care under seven ages, culminating in the current age of “Challenge”, whereby global need rises and policies, services and new models seek to bridge the gap in care quality and service provision.

This new age of challenge was illustrated by the global projected increase in deaths from 56 million to 91 million each year by 2050. He asked how death and dying could be supported on this scale?

[Tracey Bleakley](#), Chief Executive of Hospice UK, further illustrated the challenges the following day when she launched the [Hospice Care in the UK 2016 report](#). The report highlights much of the work the UK hospice sector does but estimates that there are potentially 100,000 people who have an unmet need for expert end of life care across the UK – one in five of all predictable deaths.

The challenges are big, but [Chris Pointon](#) - co-founder of the successful #hellomynameis campaign - stressed that small things can make a big difference and urged us all to lobby for change if we see something that isn't working.

The conference was one of the first occasions that he has spoken publicly about the

campaign since the loss of his wife Dr Kate Granger who died in July at St Gemma's Hospice in Leeds.

On the final day Dr Gail Eva, of the Department of Clinical Sciences at Brunel University, gave an insightful presentation entitled “[On maintaining identity and value during advancing illness](#),” which explored how rehabilitative care helped people with life-limiting conditions to “live life to the full”.

While the plenary speakers highlighted some of the challenges ahead, there were plenty of sessions describing new models, new initiatives and best practice case studies. Some notable examples include: [Research active hospices: The potential of people and partnerships](#), [Families in Distress](#), [Silent communities – those we are not reaching](#), and Nigel Seymour's [presentation on in-memory giving](#). All of the conference presentations are available on the Hospice UK website [here](#) and it is well worth looking through the headings to see if there are models and care practices that could be implemented here at the Hospice.

Celia Di Cicco, Librarian and Learning Resources Coordinator, Princess Alice Hospice



European Association for Palliative Care Conference 2016

The EAPC in Dublin this year received 940 abstracts submitted from 48 countries. Eight hundred and ninety were accepted as either oral or poster presentations.

Technology and social media is increasingly used in palliative care and research and this was reflected in some of the conference posters. Presswood et al (2016) undertook a systematic review of YouTube videos of patients talking about their experiences of terminal illness. Data was analysed using qualitative content analysis. Thirty three videos were uploaded between 2010-2015 from 12 authors. All had a terminal illness except one. Several of the videos had >100,000 views. The authors concludes that traditional systematic review methods could be adapted to review YouTube content. This type of study offers an insight into peoples use of social media to share their experience and appears to be of interest to people who use YouTube.

Another poster by Payne et al (2016) asked 'How do cancer patients use humour online during exchanges?' and 'What function does humour use appear to have?' Data included 500,000 words from cancer patients who contributed to public fora in the UK. Both quantitative and qualitative methods were used to identify humorous discursive threads. The study revealed 3 types of humour; gallows humour 'laughing in the face of death', social taboo

humour or 'toilet humour' and group specific humour that promoted group cohesion such as teasing or anecdotes. Sharing difficult things promoted mutual support. The authors found that humorous and serious content was interwoven and appeared to promote group solidarity and mutual support and may offer people empowerment in the face of adversity.

There has been wide debate as to whether the internet is a public space but there appears to be little consensus between what is considered private or personal or a space between the two (Hopewell-Kelly et al, 2016). With a growing number of researchers using the internet and social media in research there is a need for guidelines to be developed. Hopewell-Kelly et al (2016) have developed guidelines which are currently being piloted.

References

Abstracts of the 2016 European Congress of EAPC. Pall Med 2016

Hopewood, N. Baille, J. Sivell, S. Harrop, E. Bowyer, A. Taylot, S. et al. Palliative care research centres move into social media: constructing a framework for ethical research, a consensus paper. BMJ Supportive and Palliative Care 2016;0:1-6

Liz Reed, Research Lead

Princess Alice Hospice

Princess Alice Hospice conference posters 2016

European Association of Palliative Care 2016

Analysis of Hospice to Hospital Transfer. Dr Aruni Wijeratne and Dr Jacquie Phillips.

[View research poster](#)

A multi-professional educational intervention to improve and sustain participants' confidence to deliver palliative care: a mixed methods study. E Reed, R Grant, Sally Lawton, Jane Berg, Clair Sadler, Jennifer Todd.

[View research poster](#)

Hospice at Home UK conference 2016

Development of a Hospice Carers Strategy: Rebecca Trower, Head of Quality and Patient Experience Lesley Spencer, Director of Patient Care and Strategic Development.

Hospice UK 2016

Collaborate to deliver more: a proposal for Hospices to work together on information and knowledge support. Celia Di Cicco, Librarian and Learning Resources Coordinator.

[View research poster](#)

Evaluation of aroma sticks for anxiety as an extension of Aromatherapy treatment. Sharon Penny, Complementary Therapy Coordinator.

[View research poster](#)

An innovative model of enabling a Hospice IPU reach more people. John Lansdell, Nurse Consultant, Delyth Hughes, Ward Manager, Lesley Spencer, Director of Patient Care and Strategic Development .

[View research poster](#)

Continued, successful use of Ultrasound in a hospice. Bernadette Lee, Consultant in Palliative Medicine.

[View research poster](#)

Seventeen and super keen: Young people volunteering on an In-Patient Unit. Zoe Byrne, Head of Volunteering Development, Clair Sadler, Senior Lecturer, Julie Secrett, Senior Staff Nurse.

[View research poster](#)

Developing a resilient workforce: Claire McCormack Workforce Information Analyst. Gill Thomas practice educator art therapist. Emma Knivett Clinical Administrator: John Lansdell Nurse Consultant Lisa Flanagan – Senior Individual Giving Officer. Del Hughes Ward Manager .

[View research poster](#)