

Trustee Network Call Notes

Professor Christina Faull Presentation 27th January 2022

(Notes to be read in conjunction with Slides)

Professor Faull, Consultant in Palliative Medicine and Honorary Professor University of Leicester, is Research Lead for LOROS hospice and has published two award winning books on the subject. Her presentation describes the contribution of research to driving innovation and improving patient outcomes in palliative care. In this context, the CQC recognises support for research in their 'Well-Led' assessment.

'Research Active' hospices use the right evidence, in the right way to plan, deliver and evaluate care and there is a growing body of evidence that research is good for related patient outcomes and improves care, giving the examples of Cornea donation and a research study helping staff and family of MND patients.

Professor Faull described the Vision and Mission for LOROS Research and the associated ambition to be a Centre of Excellence for applied research in palliative care, translating new knowledge into 'effective and empathised personal care with patients, families and professionals'.

The associated slides comprehensively cover the information covered in the presentation in which case these notes are a high level summary supported by those slides together with points and questions raised in discussion. The consistent theme of the presentation is that research undertaken is outcome focused, an important factor in obtaining funding an area of interest to a number of those raising questions during and following the presentation.

The presentation set out the strands of work underlying the LOROS Research programme:

- Defining what research we want to do
- Developing programmes of research including external links
- Developing the culture of the organisation
- Using the findings to influence practice

These translate into 3 'Levels':

- Awareness
- Engagement
- Generating and Leading

each covered in detail in the slides with key points summarised below:

Awareness of Research includes websites, regular newsletter, study sessions, research days, annual lectures, staff surveys

Engagement in external research activities and opportunities - examples in slides including CRN, NIHR and University of Leicester; and in the LOROS PPI Programme - Patient and Public Involvement, again details in slides. Professor Faull emphasised the criticality of patient and family involvement and the associated importance of effective governance and oversight

Generating and Leading Research in particular for LOROS the close working relationship with the University of Leicester and describing significant research themes including supporting people from diverse ethnic backgrounds, communication and decision making, assisted ventilation and EOL and anxiety management in advanced disease

Finally, the importance of celebrating achievement, several examples illustrated in the last slide.

Key points from Questions and Discussion:

- The motivation of patients and families participating in research is in some cases that they feel they are able to give something back and make a difference

- The correlation between research and innovation in palliative care
- Factors critical to successful hospice research programmes include board/trustee commitment, relationships with relevant external parties and collaboration with those parties, examples referenced in slides include CRN, NIHR, University of Leicester
- Funding - obtaining funding for research relies on those networks and relationships and can be for research collaboration or LOROS specific depending on purpose of particular research initiatives
- Funding - applications can be rejected, persistence is required, don't expect quick outcomes
- Sharing research outcomes across hospices - recognition that this is an imperfect process and several ideas were put forward including making fuller use of HUK Conference (including abstracts where HUK offers training and posters), better awareness of published information and making better use of the available Portal(CPMS)
- Participants referred to examples of other successful collaborations/initiatives in the South West, North West/Lancaster University 'End of Life Observatory'
- There is NIHR Funding available for research related to inequities in death outcomes

Finally, Kate Tompkins thanked Professor Faull on behalf of the Trustee Network for her interesting and inspiring presentation. Raising the profile of research was important for all hospices including those not directly engaged in research activities and the Trustee network is a great vehicle for promoting awareness