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Issue No. 16

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## East Midlands Palliative Care Research and Audit October 2019

We were privileged to have an eclectic mix of presentations from healthcare professionals and academics across the East Midlands at this annual LOROS hosted event .

Key note speaker **Becky Whittaker**, VERDIS Real Talk Programme Development Manager, based at Loughborough University, discussed the ways in which the education resource 'Real Talk' is making an impact on training practitioners to engage in end of life talk in practice.



**Penny Millward**, from the East Midlands Clinical Research Network, talked about NIHR portfolio palliative care research. **Ed Dickson**, Clinical Research Fellow, at Nottingham University presented ICARAS an study to see if an iron infusion can improve cancer related fatigue. **Jilly Wall**, acting Consultant, in Leicester, discussed issues around engaging staff in research in a palliative setting. **Jeanna Strutinsky-Mason**, SpR, Leicester picture above,

It was very heartening to hear about so many patient-centred interventions and initiatives and to appreciate just how much research is targeted at making the patient experience better".

Dr Anne Patterson, Research Fellow at LOROS

discussed a service improvement project about emergency care drugs for massive haemorrhage in a hospice setting. **Alison Hembrow**, Treetops Hospice Care and **Sharan Watson**, University of Derby discussed the LISTEN Model used to enable support workers and volunteers to initiate advance care planning conversations in

palliative care. **Becky Robinson** SpR and **Alpna Chauhan** Consultant, John Eastwood Hospice, Mansfield, discussed findings from an audit of opioid use in syringe drivers in the community and **James Coxon** SpR, Leicester, discussed issues around Hospice waiting lists.

The event created an opportunity to support the development of research skills in the East Midlands palliative care workforce and to use evidence to discuss, challenge and improve practice and outcomes.

Report by Zobia Islam , Senior Research fellow, LOROS

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## Professor Christina Faull, Honorary Chair, University of Leicester



Alison Pilsworth, Louise Hemmings, Christina Faull, Kerry Blankley and Wendy Gamble celebrate at the University of Leicester Honorary awards ceremony.

In October we were proud to support Christina Faull as she was officially made an Honorary Professor at the University of Leicester in the Department of Life Sciences. Christina has been working in palliative medicine for nearly 30 years and has headed up the research department at LOROS since 2011.

Christina says "I am delighted to accept this honorary title. I believe it will support the important research work that LOROS does in furthering

the understanding of how to improve the care we offer. Working more closely with the University will provide more opportunities to do this."



## Why become a LOROS Patient and Public Involvement (PPI) Research Consultee?

Our LOROS PPI Research Consultees are key in helping the research team in developing, shaping and delivering research. They are a small group who meet every couple of months and discuss a variety of topics. They may be asked about the importance and relevance of the topics that the researchers are planning to study and the research questions the researchers are seeking answers to; or to give an opinion on the wording of a new questionnaire, or to talk to academics or practitioners about their research. When asked 'Why they become PPI research consultees' their reasons highlight the importance of having their voices heard:

"I am an 84 years old Aquarian. Always seeking change, if change brings improvement...Old age is a nuisance but as a former soldier I am not prepared just to sit and watch. I still feel the need to feel of some value. I still feel the need to question everything, to ask "why" and to find better ways." George

"For four years, from his cancer diagnosis until his death, I journeyed through the NHS with my Husband...Frequently we felt helpless and voiceless...We met a great number of professionals; some were understanding, intuitive, kind, others seemed indifferent, disinterested. Some made the journey a little easier, some the opposite. Shortly after my husband's death I saw that LOROS were inviting patient and public volunteers to help inform their research into end of life experience. I was grateful that the organisation wanted to hear our voices." Caroline

In the words of Caroline, one of our PPI Research Consultees: "Everyone's experience is different so I think it is important that as many voices as possible are listened to and have the opportunity to feed into future practices."

If you would like more information about becoming a PPI Research Consultee please contact [zoebialslam@loros.co.uk](mailto:zoebialslam@loros.co.uk)

## A new study aiming to help with shortage of eye donors

LOROS is one of six centres across England working on a study led by researchers at the University of Southampton. The project will investigate the viability of approaching patients in hospices and palliative care settings or who may be willing to donate their eyes after they die and is aimed at helping to tackle a shortfall in the number of people willing to consent to eye donation.

Eye tissue is needed to treat a variety of eye conditions however, currently there is a lack of eye tissue available to combat eye diseases which can lead to sight loss. NHS Blood and Transplant Eye Banks are around 20 percent below the 350 needed every month.

This research will underpin future planning by NHS Blood and Transplant eye banks as they develop strategies to increase eye and tissue donation and has been awarded £720,000 from the National Institute for Health Research (NIHR).



Lead researcher, [Dr Tracy Long-Sutehall](#) comments: “Understandably, people can hold very strong feelings about donating their eyes or those of a loved one – from concerns about disfigurement to cultural or religious considerations.

“Most people who die in the UK may be eligible to donate their eyes, but people are unaware that they could potentially donate, and we know that health care professionals can be reluctant to start conversations about the subject with patients or relatives for fear of causing upset or offence. Our study will tell us if donations could be increased if carefully managed approaches are made to patients and their families during hospice and palliative care.”

The researchers will review the medical records to assess how many patients would have been eligible to become an eye donor. Uniquely, current patients receiving care in palliative and hospice care settings will be asked to share their views about eye donation and their thoughts on discussing the issue of donation as part of end of life care planning. Carers and health care professionals will also be interviewed so that their concerns and views are gained.

# A brief overview of the research studies going on at LOROS



## **Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care**

We are very busy!



This is a study to find out about patient, family and health care professional views and uncertainties about planning for deterioration and end of life in diverse ethnic communities. At the end we aim to develop an educational tool that can be used to improve the education of health care professionals in this area.

### **Just In Case Medicines**

This study explores the experiences of bereaved caregivers with regards to having 'just-in-case' injectable medicines to manage symptoms at the end of life within the home setting. The study involves questionnaires and interviews

### **TONiC**

This is a questionnaire study looking at quality of life, and the factors that influence that, in patients with motor neurone disease.



### **Postgas**

This study is looking at nutrition and support for patients with motor neurone disease following them having a feeding tube fitted.

### **ProSec**

This study involves patients with motor neurone disease and is gathering information about the problems that they sometimes have with excess saliva.

### **MND National Register**

This study is designed to set up a register for people with all types of motor neurone disease in England, Wales, and Northern Ireland and it aims to collect some basic information about every person who is diagnosed.



### **COMMEND**

This study involves trying out a new form of psychological therapy for patients with motor neurone disease. It is a randomized study which means that patients may either receive only standard management or the new therapy.

### **PROSPECT**

This is a study involving patients with motor neurone disease and wants to understand more about the causes of this through collecting information on genetic (inherited material) make-up and environmental exposures. LOROS is helping to identify patients for this study.

### **PEACE**

This is a London hospital led, tissue donation study where patients consent, whilst alive, to donate some of their tissue after their death. LOROS's involvement is to help track patients who have consented so that their wishes can be carried out.

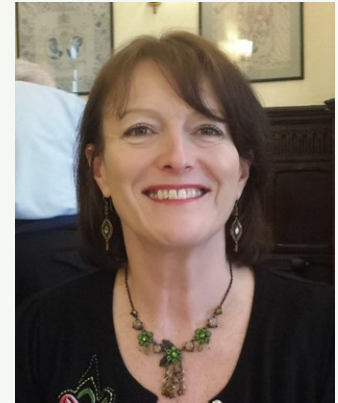
You can get more information about any of these studies by email us [research@loros.co.uk](mailto:research@loros.co.uk)



## Meet Dr Anne Patterson, Research Fellow

Anne joined LOROS in July 2019 to work on the 'Thinking Ahead' project. This is a project looking at the experiences of people from minority ethnic groups and their engagement in and with, end of life care planning. This research aligns with her ongoing research interests which relate to equality of opportunity in health and social care provision, particularly in the context of potentially vulnerable or marginalised groups.

Anne has previously worked at the University of Nottingham and Loughborough University where she gained her PhD studying interaction and communication with people with learning disabilities. Lecturing was a key part of Anne's early career but she now works principally in research. Anne's preference is in the use of qualitative research methodologies but she has also been involved in and analysed large scale surveys using quantitative research skills too.



She has worked on various studies; investigating poor practice and abuse in learning disability services, the evaluation of care at home services for people at the end of life, the exploration of the concerns of LGBT elders in accessing health and social care services and most recently a project developing resources to safeguard adults with learning disabilities at risk of forced marriage. Anne also provides research support on a number of smaller projects to do with safeguarding adults with learning disabilities, both as a family carer herself and a research professional. At the heart of every project that Anne undertakes is a desire to ensure everyone's voices, and particularly those from potentially marginalised groups, are heard and that any findings from research translate into better practice and better support services.

### Breaking News

Natalie Ayton, Research Nurse has a poster presentation at the International Palliative Care Congress in March 2020: *'Recruiting MND patient research participants: I thought we would have more.'*



### Research Events at LOROS Professional Development Centre

**Annual lecture**

**March 24th 2020  
5.30 pm for  
6-7pm lecture**

**A Good Death in Dementia  
Speaker  
Karen Harrison-Dening**

**East Midlands  
Research and Audit**

**September 29th 2020  
1.30-5pm**

**Please let [christinafaull@loros.co.uk](mailto:christinafaull@loros.co.uk)  
know if you want to present**