



**March 2022**

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any of the articles in this  
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[research@loros.co.uk](mailto:research@loros.co.uk)

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## **Big ambitions for the Centre of Excellence in the next five years**

There has been an extra buzz at LOROS over the past six months since the exciting news that we received a grant to support our research over the next five years. With the University of Leicester we are building a great team to take forward a programme of work to improve care for patients and their families.

### **Research in partnership**

We are delighted that we have this opportunity to improve care for people living with advanced illness and frailty. I am very proud of what the team at LOROS have achieved in research, education and care which creates the strong platform for this next stage. We are determined to make a real difference to care.

The Partnership with the University is a step change in this.



**Professor Christina Faull,  
Consultant in Palliative  
Medicine & Research Lead**



**Dr Chris Williams, GP and  
LOROS Clinical Lecturer,  
University of Leicester**

### **Our research themes are:**

- Communication and decision-making
- Symptom management
- Palliative care for older people and their family

## Big ambitions for the Centre of Excellence in the next five years continued

We are developing a number of studies that will make a real difference to people locally and which will have wider importance. In 2022 this includes:

### **Preparing for change:**

Examining the potential for volunteer peer support mentors for family of people in care homes to think ahead and prepare for decisions about future deterioration and the end of life.

### **Pre-transfer clinical discussion and assessment:**

Development and evaluation of a new clinical pathway to support frail care home residents who become unwell.

**Tolerance of Uncertainty:** To understand how older people, carers and clinicians interact in complex clinical situations and co-develop information for patients and training materials for professionals.

### **SPARS:**

Symptom Palliation when Non-Invasive Advanced Respiratory Support is used at end of life for treatment of respiratory failure.

Assessing the acceptability and feasibility of **cranial electrotherapy stimulation** as a treatment for **anxiety** in patients who experience **breathlessness** due to advanced chronic respiratory disease.

**CRISIS Study:** Conversations in COVID-19 about end of life Readiness in Serious Illness situations. To understand the experiences and perceptions amongst ethnically diverse patients with end-stage kidney disease.

## Centre of Excellence

An integrated approach of care, learning and leadership.

- Knowledge generation
- Knowledge translation
  - ❖ Workforce development
  - ❖ Advocacy
- Impact
- Improved care



All this and more alongside the studies that patients at LOROS take part in that have been developed by other researchers in the UK and internationally (See page 8). It's going to be a very busy year!

Keep an eye on our webpages [here](#)

# LOROS there's been lots going on

## Congratulations to our LOROS Research Team flying the flag

### LOROS Research Team had three presentations at 'The Annual World Congress of the European Association for Palliative care Conference'

We are delighted that the 2 poster abstracts received a rosette award at the conference



"Emotion Work and Emotion Management for Both Participants and Researchers in Interviews about Advanced Illness and End of Life Care"

"Being known: How people from minority ethnic communities with terminal illnesses navigate the healthcare system as 'whole' Individuals with potentially diverse needs"

## Just in case medicines

Christina Faull gave an oral presentation of findings from the 'Just in case' medicines project which explored the experiences of families of having these medicines at home to help manage symptoms in the last days of life.

### Christina said

*"I am getting more used to conferences that are virtual. It was good to be able to share findings from two areas of research with a big International audience. You can see a recording of my presentation [here](#)*

**There are some important points for practice which include:**

*The need to talk more with relatives about the medications: what problems may arise as the person gets less well that they will be used for, who will use them and how they might ask for this help.*

*To acknowledge that sometimes people find being giving the drugs*

*is the first time they really realise that the person is going to die*

*To be clear that the drugs are used to manage symptoms when someone can't swallow tablets and they are NOT used to intentionally shorten or end life. (the phrase 'end of life drugs' can be misinterpreted)*

*Give people instructions as to what to do with unused medications*



## LOROS Annual Lecture: 'Muslim Perspectives on end of life'

### Guest speaker Dr Mehrunisha Suleman



Dr Mehrunisha Suleman is the Director of Medical Ethics and Law Education at the University of Oxford. A medically trained bioethicist and public health researcher, she recently led the Health Foundation's COVID-19 impact inquiry, reviewing evidence and conducting novel analysis on the impact of the pandemic on health and health inequalities.

She is currently conducting research and public engagement on a Qatar National Research Fund project on Genomics, Islamic Ethics and Public Engagement.

Dr Suleman has also been working as a researcher at the University of Cambridge conducting ethical analysis of the experiences and inequalities faced by patients and families trying to access effective palliative and end of life care services.

Mehrunisha is a trustee at the Arthur Rank Hospice in Cambridge.

We do hope you are one of the 205 who booked to attend this virtual lecture on 21st February 2022. A recording of the lecture can be found [here](#)

### News about our team.....

#### Meet our new Research Associate Dr Penny Smith

I started as a Research Associate based in the LPDC at LOROS, in September 2021. I am working across a number of projects focused on diversity and end-of-life care planning and carers amongst others. I'm looking forward to working with patients, carers and health care professions and will begin to gather data on the projects. I am primarily a qualitative researcher so really enjoy meeting and interviewing people and developing an in-depth understanding of issues, to get to grips with answering our research questions. I joined at a busy time with projects beginning to develop and plans for a wide-scale research programme under way. My background is in Social Science research and I began my career as a contract researcher at the University of Birmingham where I spent 10 years working on a variety of research projects based in the School of Education. These projects varied from multi-disciplinary studies with health, psychology and social policy to smaller-scale projects focused on special educational needs and disabilities for example. During this first period at Birmingham I studied for and was

awarded a PhD in Education on school governance in Wales which involved a number of years conducting interviews in schools and education departments across Wales. Before joining LOROS I spent an additional four years back at Birmingham University and on this occasion I worked in the Business School on projects relating to diversity and inclusion: this included studies on Shared Parental Leave in the workplace and a major project for the Ministry of Defence on the lived experiences of women and people from ethnically diverse communities in the UK armed services and the Civil Service. Prior to that period of employment at Birmingham I worked at Warwick and Coventry universities working on studies focused on Education in the Midlands. It's good to be working at LOROS, a charity local to me, where I can see the difference research can make.



## Loughborough University Verdis Team and LOROS working together

The VERDIS research team has published two research papers based on analyses of consultations that they video recorded at LOROS between 2014 and 2017

### Publication:

#### **Practitioners Dilemmas and Strategies in Decision making Conversations Where Patients and Companions Take Divergent Positions on a Healthcare Measure**

This paper (by Pino, Doebling, and Parry) examines cases in which a patient and a companion express divergent positions about a healthcare measure (such as walking aids, homecare, or medications); that is, one supports the measure whilst the other opposes it. The paper examines the communication skills that healthcare practitioners (doctors, physiotherapists, and occupational therapists) use to manage these delicate situations. The paper can be found [here](#).



Dr Anne Doebling



Dr Marco Pino



Professor Ruth Parry



Dr Laura Jenkins

### Publication:

#### **Providing Opportunities for Patients to Say More about Their Pain**

This paper (by Jenkins, Parry, and Pino) examines a communication skill that doctors sometimes use when asking about the patient's pain: repeating the patient's answer. The paper shows that this skill can be used to give patients opportunities to say more about their pain without asking overtly. The paper can be found [here](#). The team also wrote a short summary about this paper, which you can find [here](#).



East Midlands  
Research and  
Audit 1/2 Day

Tuesday  
27th September  
2022  
1.30-5pm

Look out for the  
booking details

Virtual event based  
from LOROS  
Professional  
Development  
Centre

## More news about our team.....

### Meet our new Research Manager, Tara Maitland

I am the new Research Manager for LOROS. I have a passion for research and take pride in ensuring that research is translational and completes the cycle from bench to bedside. I strive to do this at LOROS by supporting quality research that allows opportunities for staff working in palliative and end of life care and patients and service users to be involved in research and thus shape care of the future.

I have previously worked in different guises at the University Hospitals of Leicester, most recently as the Governance Officer and Project Manager for the Cardiovascular Theme of the Leicester Biomedical Research Centre. I am delighted to bring my rich governance and project management background to LOROS to ensure the highest standards of research activity and compliance.

I am joining LOROS at a really exciting time in research and I am truly eager to be a part of this. I am charged with enhancing LOROS' research portfolio and collaborations, sharing my expertise and experience to guide and support both new and existing researchers.

I also have a role within the East Midlands Clinical Research Network (EM CRN), driving an increase in the quantity of inclusive, quality

research in palliative care across East Midlands. A key objective is to empower hospices across the East Midlands to become research active in a collaborative and supported way. I can support hospices in research related activities which span from feasibility and study set up processes to close down and archiving.

It is hoped that these combined LOROS and CRN objectives will see a rise in research activity across the East Midlands.

I look forward to the exciting times ahead with the Research Team and beyond.



### Farewell and a huge thank you to Dr Anne Patterson and Matilda Hanjari



**Matilda Hanjari**

We say farewell to Anne and Matilda, two key researchers on the NIHR funded study *Thinking ahead about medical treatments in advanced illness: A qualitative study of barriers and enablers in end-of-life care planning with patients and families from ethnically diverse backgrounds*. They have been a huge asset to the study and fantastic colleagues. The study has now been completed with their tremendous effort and we wish them both every success in the future.



**Dr Anne Patterson**



***Congratulations! LOROS was the winner of the 2021 Hospice UK award in acknowledgment of our contribution to National Institute for Health Research portfolio***



The LOROS Research Team were delighted to receive this award. Every department in LOROS is involved in improving care through research and our commitment to be able to offer patients and families the opportunity to participate. Our research nurses Natalie Ayton and Naomi Seaton, supported by Wendy Gamble, our recently retired research manager, have been instrumental in enabling staff to identify and approach patients as well as

tremendously skilful in sensitively working with participants who, as everyone in palliative care knows, are often very unwell and facing huge challenges. We would like also to thank our PPI group for the enormous support and passion for this work.

***Research at LOROS: Activity and achievements 2020-21***



**12 University Collaborations**



**5 Conference Presentations**



**28 Research Participants Recruited**



**6 Grants Applications**



**11 Research Studies  
1 Excellent Team**



**8 Focused People,  
Research Income**



**£226,558**



**5 Journal Publications**



**127 Participants Screened**



**1 Annual Lecture  
'A Good Death in Dementia'**



**24 Patient and Public Involvement**



**8 Partnerships**

## Update on our Research Studies



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

We have launched the e-learning session to support health and care staff in offering people from diverse ethnic backgrounds effective, sensitive opportunities to discuss deterioration, dying and advance care planning. You can access the session [here](#)

### Preparing for Change.

We are starting to recruit family members and care home staff participants to this study to understand the experiences of family who support a loved one in a care home who is unable to make decisions themselves about their treatment and care. We want to explore whether a peer mentor would be useful to develop.

Contact [fawn.harradhyde@leicester.ac.uk](mailto:fawn.harradhyde@leicester.ac.uk) for more information



**COMMEND** This is a randomised controlled study of a new form of psychological therapy called Acceptance and Commitment Therapy (ACT) in persons diagnosed with motor neuron disease to see if it improves quality of life. Participants will either receive the ACT in addition to their usual care or usual care alone.

### The MND Register for England, Wales and Northern Ireland

The purpose of the study is to collect and store information about every person with MND in the UK. The data collected will help researchers understand the progression of disease, how many people have been diagnosed with MND each year and understand where people that are diagnosed live which can help with future care planning.



### PEACE

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

### MiNDToolkit: a novel online platform for the management of behavioural symptoms in MND

The aim is to test the feasibility of the MiNDToolkit online intervention. The study will support carers of people with motor neurone disease with behavioural symptoms. Health care professionals will be trained and can re-enforce the MiNDToolkit content, in particular through role playing during consultations.



This is a randomised controlled trial that will research a nutritional support package designed for people diagnosed with Motor neurone disease. Half the participants recruited will receive the OPTICALS support package and half will continue with their usual care. Evidence from some smaller studies suggests that changes to dietary intake may improve functional outcomes and slow ALS disease progression.

### Vent MND

#### Exploring decision making with patients with MND using home ventilation

A study to explore patients' and family members' experiences of end of life decisions about continuing or withdrawing mechanical ventilation in Motor Neurone Disease (MND). This is a Single-centre, qualitative study.

