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For more information about any of the articles contained within this newsletter please contact: research@loros.co.uk

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Improving End of Life Care for People from Black, Asian and Minority Ethnic Communities

We are delighted to share the news that the National Institute for Health Research have awarded the UHL and LOROS funding for this 30 month research project starting in November 2018.

The LOROS team work with colleagues from Leicester, Nottingham and the Open Universities as well as in hospices, general practices and acute and community trusts to deliver this project.

We are also working closely with community organisations and are so pleased that Irfhan Mururajani, with his experience in community engagement and of end of life care, is our Patient and Public Involvement co-applicant.



In this project we will explore the diversity of approaches to thinking ahead about deterioration and dying and the barriers and facilitators to discussions and planning. The project aims to improve care for patients by translating findings into resources to support the training of health care professionals. Our past work has shown that many professionals lack confidence in both end of life care planning (EOLCP) and in supporting patients from minority ethnic backgrounds and their families suggesting compounding risks for patient outcomes.

Improving EOLCP and enabling equitable access to palliative care are key strategies in government policy but people from minority ethnic communities are disadvantaged. The policy promotes EOLCP to enable people to be cared for in the way that they prefer. However, little is known about how current policy and practice 'fit' values and beliefs of different communities.

Recruitment will take place across Leicestershire and Nottinghamshire of patients from a diversity of faith and ethnic backgrounds with a range of terminal illnesses. We will also recruit their family caregivers and health professionals that support them. In Year 3 we will be holding workshops to consult on the findings.

How do doctors make decisions about surgery in patients who are frail? A Master's study by Dr Rich Kitchen

I held the post of Clinical Education Fellow in palliative care at the Centre for Promotion of Excellence in Palliative Care at De Montfort University (CPEP) and LOROS from 2012 to 2014. This was an exciting time in my professional career and I am still grateful now for the support from Health Education East Midlands, CPEP and from LOROS during this time, as well as from my supervisors Professor Christina Faull, Dr Gordon French and Dr Rakesh Patel. Although this was some time ago the work is on-going and have recently submitted my research for journal publication.

My main remit at the outset of the post was to develop educational resources in palliative care for surgeons and anaesthetists. To power this, I decided to look into what surgeons and anaesthetists find challenging about palliative care in their context. I developed the research question "How do doctors make decisions about surgery in patients who are frail?" Frail patients were chosen as a number of criteria had been published for defining this specific group, making them easier to identify than patients with palliative care needs.

To answer this I carried out a qualitative study with a strategy informed by grounded theory. Using semi-structured interviews supported by a case vignette, I interviewed three consultant and three trainee surgeons, and three consultant and three trainee anaesthetists, as well as carrying out a paired interview with a surgeon and anaesthetist. Interview transcripts were analysed using framework analysis, a structured form of qualitative analysis.

Four main themes were found: Concepts around frailty, shared decision-making, learning, and factors in decision-making. Doctors reported having received little training in working with frail patients, which increased the challenge of the decision-making process about surgery. Numerous factors were used to decide whether to offer surgery to a frail patient. Surgeons and anaesthetists jointly sometimes, but not invariably, made this decision. If surgery was possible, shared decision-making between doctors and patients often took place.

I wrote the study up as a Master's dissertation. Since this time, research into frailty more generally has expanded. This has again looked into defining frailty, but also the relevance of frailty on health outcomes, including around a number of different types of surgery. Whilst it has taken some time to write this research up for publication, the relevance of the work remains high, and it is important for the findings to be more widely available.

For more information about this work, contact richard.kitchen@nhs.net
Consultant in Palliative Medicine, Coventry and National APM e-ELCA lead



Richard is also a very keen cyclist!



Inspiring Event

The 10th World Research Congress of the European Association for Palliative Care

Dr Zoebia Islam
LOROS Senior Research Fellow
Reports from Bern, Switzerland.

'Attending the congress was an excellent opportunity to meet experts in the field, discuss research, gain new ideas and new knowledge on how to improve treatment and care for patients and their families.'



In May our Senior Research Fellow Zoebia was privileged to attend the European Association for Palliative Care (EAPC) congress in the beautiful and historic city of Bern, Switzerland. The EAPC is a membership organisation dedicated to the promotion and development of palliative care throughout Europe and brings together researchers and clinicians in palliative care.

The conference programme included presentations and discussion sessions on: Cancer and palliative care; Public health and policy; Ageing and palliative care; and research methods.

The LOROS research team work with Leicester University medical student Lucy Taylor and Lecturer Helen Eborall had an abstract published online entitled: *Thinking Ahead about Medical Treatments in Advanced Illness: The Complexities of Supporting Diverse Communities in Leicestershire* in a special edition of Palliative Medicine by Sage Journals.

Professor Irene Higginson delivered the inaugural Vittorio Ventafridda lecture entitled: *Future-proofing Dame Cicely Saunders' Centenary of Change: Integrating research, education and clinical care* which was particularly inspiring recalled Zoebia.



Public and Patient Informant (PPI) Research Consultees

Our Partners in Research

In the last year we have been fortunate to have the input of much valued research PPI consultees who play a key role in developing new projects. They help the research team decide on the importance of the potential projects and the research questions to answer. They also guide wording of participant information sheets and other study documentation and help researchers to assess the potential burden and impact of participating in a study. Through their own knowledge and networks they aid participant recruitment and support the way in which the research findings are disseminated.

If you would like to know about becoming a research consultee we'd love to hear from you! research@loros.co.uk or 0116 2318498

I've seen first hand how important it is to consult the public and patients on proposed research projects. It allows the Hospice to obtain a balanced view on research and ultimately improve care practices for the patients. Such a great way to get involved in the development of services.

Dipti Patel PPI consultee

Dipti Patel, a current Research PPI Volunteer shares her thoughts:

Focus on improving care in heart failure

Ali Pilsworth
Practice Educator

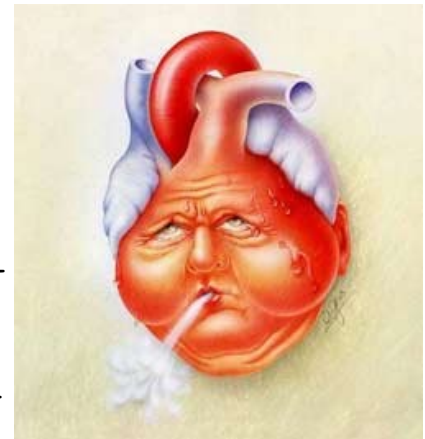
The British Heart Foundation estimate that over half a million people in the UK are currently living with heart failure (HF). Clinical care for those living with HF is excellent and is focused on relieving symptoms however people dying from HF can really benefit from specific, personalised care that can help improve their quality of life until they die. Hospices may be best placed to provide this.

LOROS has been awarded a grant from Hospice UK to improve the care of patients with heart failure by raising awareness of the value of earlier referral to palliative care and to develop staff knowledge and skills

The project has three strands of work; education for LOROS care teams, education for acute and community trust staff and awareness raising of hospice services with clinical staff and in the local community.

Baseline assessments will be undertaken with staff that attend education events allowing us to tailor the learning to each cohort's needs and baseline understanding.

We are currently carrying out mid-point assessments and will gather end-point data through conversation and questionnaires. This will include satisfaction with learning and also map their progress in knowledge and confidence.



Our new thinking space

A wonderful legacy of our colleague and friend Idaliza Nukis



In July we gathered to remember Idi with her Mum Jane and to honour her enormous contribution to the education and research teams and to the life and work of LOROS.

We now have a lovely bench we can sit on in a corner of the garden near the Professional Development Centre and carved into its back rest is *Come sit with me and rest awhile.*

The bench provides a quiet spot to ponder and gather energy and together with a tree that we plan to plant in the autumn as a celebration of our NIHR award (and all the paper that this has taken!) this area of the garden will be our *Thinking Space*. A little oasis in the bustle, emotions and stresses of work.

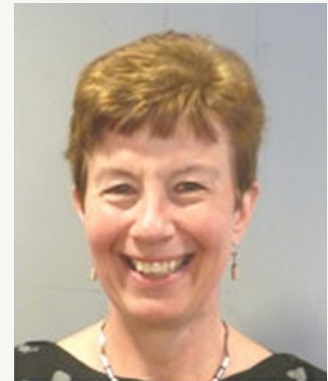


Meet our Research Nurse Karen Hamilton

Karen joined the Research Team in March working as a Research Nurse (Bank). This is Karen's first experience of working as a research nurse and she is very excited to be pursuing this new role. She has worked at LOROS for over 8 years, initially as a Practice Educator primarily working alongside community and mental health staff. Having the privilege of training LOROS staff and volunteers has enabled Karen to develop excellent working relationships, which are extremely helpful as a Research Nurse. Hopefully, over time she will inspire staff, patients and volunteers to develop a greater interest in research.

Improving the quality of care is at the heart of Karen's working philosophy. Since leaving the Education Department she has joined the LOROS nurse bank and is a volunteer for the Home Visiting Team. She also has time now to develop her career as a Yoga Teacher.

Karen's long nursing career has given her many transferable skills to bring to her new role. During her time as a District Nurse she completed further studies to extend her knowledge and skills in palliative care and as a DALE (Decisions at Life's End) Nurse she was more involved in audit which helped to fuel her interest in research.



Annual LOROS Lecture 2019



**Life's hard and then you die:
exploring end of life
concerns within the homeless population
Wendy Ann Webb
Advanced Nurse Practitioner, Worcester**

**Thursday 28th March 2019
6.00pm to 7.00pm
Refreshments from 5.30pm
LOROS Professional Development Centre
To book a place email:
research@loros.co.uk**

