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

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Public and Patient Involvement (PPI): Challenges and Opportunities in COVID 19

At LOROS we are privileged in having the support of PPI research consultees and project specific PPI advisors. They help us to improve the quality and relevance of our research. The COVID 19 pandemic has had an impact on PPI engagement nationally. Our PPI contributors have continued to offer us their guidance and advice in our current work and in developing future research.

Caroline a valued PPI research consultee tells us:

'I am happy to continue to be a PPI research consultee because whatever else has changed I think it is still the case that the more viewpoints that are included in the planning and conducting of research the more relevant it will be.'

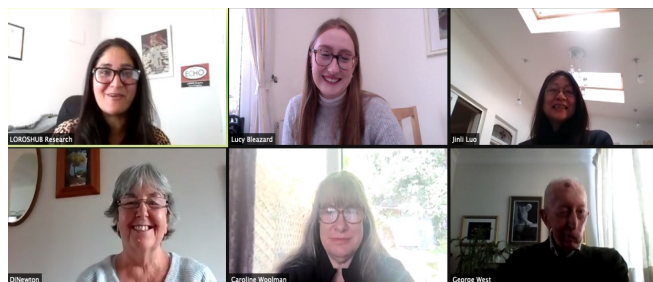
Whilst Irfhan the PPI lead for the 'Thinking Ahead study' in which we are exploring the barriers and enablers for end of life care planning for Black Asian and Minority Ethnic communities goes on to say:

'It has been a real honour and privilege to be involved in this pioneering work, and what has been achieved so far will greatly enhance the end-of-life care delivered by healthcare professionals. The global pandemic has further reinforced the

critical importance and need to share and understand the spiritual and cultural requirements of those patients receiving palliative care. The impact and loss of life due to COVID-19 has been felt by every single community, culture and faith worldwide. Healthcare staff have had to provide comfort and strength to patients and their families during these unprecedented times, and it is more important than ever to ensure that every person is able to receive all of the non-clinical elements of care that they deserve.'

All meetings are being conducted via virtual platforms such as ZOOM or simply over the phone, with our PPI guiding us on their preference. If you are interested in becoming a PPI Research Consultee please contact: ZoebiaIslam@loros.co.uk

Report by Dr Zoebia Islam,
Senior Research Fellow, LOROS



COVID 19 Research at LOROS

In the first wave of COVID LOROS took part in an international study led by the Cicely Saunders Institute aiming to understand both the impact of COVID on Hospices and palliative care services and the palliative care needs of patients. As part of this work the medical team at LOROS reviewed the notes of 12 patients who we had cared for on the hospice ward.



The key messages from analyses so far are that:

Palliative and hospice care services responded actively during the COVID-19 pandemic but were often ignored from national and multinational pandemic responses. Palliative and hospice care services adopted 'frugal innovations' (improvised, unplanned, and low cost – yet effective - solutions) in responding to the pandemic.

Services provided direct care and education in symptom management and communication; 91% changed how they worked.

Care often shifted to increased community and hospital care, with fewer admissions to inpatient palliative care units.

Shortages were common. Of services, 48% reported shortages of Personal Protective Equipment (PPE), 40% staff shortages, 24% medicines shortages, 14% shortages of other equipment. Considerable time and energy was expended trying to mitigate against the effects of these shortages.



The recommendations are:

There is a need for better recognition and integration of palliative care into national health systems. This is particularly the case for charity managed services and those providing care in people's homes.

The different groups of people severely affected by COVID-19 should be better recognised. A parallel planning approach may be needed for patients with uncertain trajectories.



The role of free standing inpatient palliative care units should be proactively considered in a second pandemic wave: could their staff be diverted to the community (as occurred in some settings in our study), could they be diverted to hospital palliative care teams or care homes (both settings needing additional support), or could units provide an alternative or rehabilitation/step down care from hospitals?

You can watch Professor Higginson's presentation at the European Palliative Care conference [here](#) and read more in some preliminary papers from the study

[Advance Care Planning during COVID-19](#)

[Caring for people dying from COVID-19](#)

[Innovation and practice change: Necessity is the mother of invention](#)

LOROS there's been lots going on

LOROS is very proud that our study of how archaeology might be used to promote open discussion about death and dying has been published in this renowned journal.

Our project aims were threefold: firstly, to explore the value of archaeology for facilitating discussion around death and bereavement; secondly, to enable reflection on contemporary attitudes to death and bereavement, challenging norms and biases; and thirdly, to understand the potential impact of workshop attendance on individuals, professional practice and patient care.

The paper was awarded the 'publication of the month' by Bradford University.

The Chief Investigator Dr Karina Croucher, archaeologist at Bradford said

"I am delighted and proud to see the publication of this Interdisciplinary research and I'm looking forward to seeing how others will take on and build on our findings going forward."

This paper outlines our findings, along with a reflection on why and how we believe the project succeeded.

Want to know more, you can read the paper [here](#)



Breaking news: our big study has been extended



We are delighted to share with you that we have been granted a 5 month extension to our study 'Thinking ahead: Exploring Understanding Experiences and Decisions in End of life Care'.

This is a qualitative study exploring barriers and enablers in end-of-life care planning with patients and families from Black, Asian and Minority Ethnic backgrounds.

The study will now end 30th September 2021

Dr Zobia Islam, Senior Research Fellow commented

'Improving end of life care planning and enabling equitable access to palliative care are key strategies in government policy, yet little is known about how current policy and practice 'fit' values and beliefs of ethnic minority groups. It is vital that we continue this work to help improve the experience of end of life care for ethnic minority patients and their families.'

LOROS Annual Lecture: A good death in dementia

Guest speaker Dr Karen Harrison-Dening

We are delighted to say, our annual LOROS Lecture, A Good Death in Dementia went really well and attracted 110 virtual delegates.

The lecture was open to anyone working with people affected by dementia, including health and social care staff and students, care home and domiciliary care staff, volunteers and the public.

It was a truly insightful lecture by Dr Harrison-Dening who has over 40 years' experience in nursing, has a PhD in advance care planning and end of life in dementia and is a pioneer and national leader in this field with many publications.



Dr Karen Harrison-Dening

If you were unable to attend on the day then you can watch the entire lecture [here](#).

We presented at the Research Forum hosted by the Leicestershire Partnership Trust



On 7th April 2021 LOROS researchers, Dr Anne Patterson and Matilda Hanjari, presented preliminary findings and promoted discussion in a virtual Research Forum hosted by the Leicestershire Partnership NHS Trust.

The forum focused upon our study, 'Thinking ahead about medical treatments in advanced illness: Exploring and understanding experiences of patients and families from Black, Asian and Minority Ethnic (BAME)

backgrounds'; a major project funded by the NIHR being conducted by the LOROS Research Department.

The forum was attended by 15 research forum members attended and discussion was lively; members were particularly interested in how it had been possible to conduct the research in a compassionate and patient-centred way given the sensitivity of the research topic and how a longitudinal case-study approach had helped to achieve this.



Research in University Hospitals Leicester

Rachel Dowling, Head of Research Communications

One heartening piece of news during this pandemic is the continued success of Leicester's COVID-19 research, where more than 27,000 patients, staff and volunteers have taken part to help us tackle coronavirus.

Leicester's Hospitals is by far the highest recruiting trust to the RECOVERY trial, which is investigating the effectiveness of different treatments for COVID-19. 1360 people in Leicester have taken part in the study, which has already found that a low-cost steroid called dexamethasone significantly reduces the risk of dying for patients on oxygen or needing ventilation. Just as importantly, it has also shown that hydroxychloroquine, convalescent plasma, colchicine and lopinavir have no clinical benefit for patients.

While clinicians and scientists learnt much about the acute phase of illness during the first wave, there is still limited information on the longer term health impacts of COVID-19 on people who have been discharged from hospital. The National Institute for Health Research (NIHR) Leicester Biomedical Research Centre is leading an £8.4 million study called PHOSP-COVID, involving 20 institutions across the UK, to understand why some people make a full recovery while others continue to have symptoms long after the initial illness - a condition known as Long COVID. The study will recruit 10,000 patients over the coming months and follow them for up to 25 years.

The long term plan to make our way out of the pandemic is to find a vaccine. Leicester has been supporting the ENSEMBLE2 vaccine trial and has recruited 600 volunteers, the third highest to this trial in the world! People aged between 18 and 40 years from an ethnic minority background can still register to take part: [here](#).



University Hospitals of Leicester
NHS Trust



Nurse Researcher in ICU

Back in April, academics at the University of Leicester first raised the alarm about the disproportionate impact of COVID-19 on people from ethnic minority backgrounds compared to white Europeans. It follows that in our proudly diverse city, a research team will lead a £2.1million study called UK-REACH to investigate the disproportionate impact of COVID-19 on healthcare workers from ethnic minority backgrounds, in conjunction with the major healthcare professional bodies in

News about our team.....

Our amazing Research Manager, Wendy Gamble has retired

Wendy writes 'When I joined LOROS as the Research Manager in 2016 it was like coming home, to an organization that I'd worked for as a nurse soon after the hospice opened way back in 1985 and somewhere that's close to my heart.

I've been fortunate to work with a great team at LOROS who all complement each other in our areas of expertise and knowledge, working well together to deliver research safely and effectively.

It's so important that everyone has the opportunity to be involved with research if they wish to and LOROS has been very supportive and has embraced research across the organization meaning that it's now embedded within our care. Research at LOROS has grown hugely over the last five years in infrastructure, the number of varied research projects that we're undertaking and in reputation.

As I edged towards my retirement, I reflected on my time working for this very special organization, I am extremely proud of what we've achieved in the last five years.

LOROS is now recognized as one of the major contributors to hospice research across the UK and it's been my pleasure and a privilege to have been a part of this.

Wendy was thrilled with her memory book and beautiful reclining garden chair
We wish Wendy a healthy and happy retirement and thank her for all her knowledge, support, leadership and friendship.



... more news about our team...congratulations

Congratulations to Matilda Hanjari, LOROS Research Associate in gaining a PhD studentship at Demontfort University. Her PhD, over 3 years, will be on 'Experiences of amputations; looking at the religious and cultural factors affecting disposal pathways. We are pleased to confirm that Matilda will continue to work 2 days a week on the Thinking Ahead Study.



Congratulations to Dr Zoebia Islam, Senior Research Fellow at LOROS, who has accepted an Honorary Lecturer post at the University of Leicester which is a great opportunity for Zoebia and LOROS. Great news Zoebia

Research at LOROS: Activity and Achievements 2019-20



12 University Collaborations



19 Conference Presentations



111 Research Participants Recruited



6 Grants Applications



9 Research Studies



8 Focused People, 1 Excellent Team



£229,516 Research Income



2 Journal Publications



166 Participants Screened



Annual Lecture Postponed



25 Patient and Public Involvement



8 Partnerships

Update on our Research Studies



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

This is a study to find out about patient, family and health care professional uncertainties and views about planning for end of life in South Asian 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.

COMMEND

The purpose of this trial is to see whether a new form of psychological therapy called Acceptance and Commitment Therapy, provided in addition to usual care can improve quality of life in people with motor neuron disease compared to 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.



POST GAS

The purpose of this study is to understand the best way to manage the diet for people living with motor neurone disease (MND) after they have a feeding tube. The aim is to produce evidence based guidelines, which will ensure everyone receives the best care and advice regarding nutrition after they have a feeding tube.



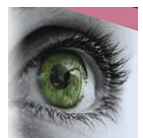
This is a questionnaire study for people diagnosed with MND. The questionnaires look at how living with MND affects quality of life, which will go on to improve care in the future.

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.

Eye Donation

Researchers from The University of Southampton are seeking to explore the views and opinions of patients and carers of patients about discussing the option of eye donation as part of care planning. LOROS's involvement is to approach health care professionals, patients and carers that would be willing to undertake an interview on their views of eye donation with the Southampton team.



NEW STUDIES – COMING SOON



The purpose of the study is to test a nutritional support package designed for people diagnosed with Motor neurone disease. This is a randomised study therefore half the people recruited will receive the support package and half will receive usual care.

On 29th September 2020 the above event, hosted by LOROS and chaired by Professor Christina Faull was held virtually. The event attracted 74 delegates and hosted seven presentations, each illuminated varying aspects of palliative care research activity.

Dr Anne Patterson, LOROS reported the emerging findings of the Thinking Ahead Project, being conducted at LOROS which is a 30 month project (now extended to 35 months) which explores how terminally ill patients from Black Asian and Minority Ethnic backgrounds and their family care givers think ahead about deterioration and dying and engage with healthcare professionals to optimise care.

Penny Millward, CRN East Midlands gave an overview of the portfolio of Palliative Care research underway or has recently been completed in the East Midlands, painting an encouraging picture despite the challenges associated with the impact of a pandemic.

Dr David Wenzel, UHL and LOROS, delivered a COVID-related presentation discussing the UHL experience of managing respiratory distress in patients that are dying from COVID.

Dr Becky Payne, Kettering Hospital presented on respiratory failure which explored salient matters around the withdrawal of non-invasive ventilation in patients with respiratory failure.

Dr Kerri McEvoy, UHL presented the findings of a survey of bereaved carers about their experiences of 'Just in Case' medicines.

Dr Chris Williams, academic GP and researcher, reported on the findings from a pilot study conducted by the University of Leicester regarding clinical discussion and assessment of frail patients in care homes and their possible transfer to acute care.

Dr Becky Robinson, Royal Derby and Dr Rebecca Boyland, University of Nottingham reported results from an audit of opioid use in syringe drivers.

Just a snap shot of the comments on the day

'really interesting presentation' 'great visual representation' 'A really helpful vignette'
'Excellent work' 'Thankyou everyone, really useful afternoon'

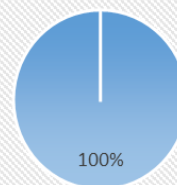
'Thanks for a really interesting afternoon - I have learnt a lot and there's some great work going on locally'

The varied array of research activity showcased at the event was a tribute to all of the researchers and participants willing and able to conquer any challenges associated with the last year and to progress the palliative care research agenda in the East Midlands. One of the learning objectives of the day was to use evidence to discuss, challenge and improve practice and outcomes. The lively debate throughout and Q&A's after each presentation served this purpose magnificently. As the world began to 'unlock' for a third time the research being undertaken in the East Midlands as showcased at this event would suggest we really can as researchers look 'Forward' in Hope'.

Reported by Dr Anne Patterson, Research Fellow, LOROS.

Has the afternoon met the stated objective?

To use evidence to discuss, challenge and improve practice and outcomes



■ Yes
■ No



East Midlands
Research and
Audit

Tuesday
28th September
2021

Book here now
here
to secure your place

Virtual event based
from LOROS
Professional
Development
Centre