



**This Issue:**

- Page 1 New Professional Development Centre at LOROS
- Page 2 Wendy Gamble, Research Manager wins award
- Page 3 PIPS2 Study Update
- Page 4 Managing Medicines Research
- Page 5 Thinking Ahead Study
- Page 6 60 seconds with.....Christina Faull
- Page 7 Continuing Bonds and Dying Matters Week
- Page 8 Dates for your Diary
- Page 8 LOROS Bursaries

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

## Professional Development Centre Improving Care

*The eagerly awaited new professional development centre will open its doors in September 2017.*

We are delighted that the very first event will be the East Midlands Audit and Research half day on the afternoon of 21<sup>st</sup> September. We are looking forward to seeing many of you at this event to celebrate what has been happening in palliative care research across the East Midlands in the past year and to showcase our wonderful new Centre.

**Book in for the free event, simply e-mail [research@loros.co.uk](mailto:research@loros.co.uk)**

The Centre will provide state of the art learning facilities including a clinical skills centre, lecture and seminar rooms, many break out spaces, the library and will be the new base for the research department.

This really feels like an important new phase for research@LOROS. The new facilities will allow our many visiting researchers to feel part of our team and fully supported in their data collection. The research team has grown and the activity has increased over the past three years; we are bursting at the seams. It's not just about physical space however, it's also about an environment and culture for learning and research@LOROS. As an organisation which provides specialist palliative care a key part of the mission is to share knowledge through education and training in order to influence the care of patients and families way beyond those we can have direct contact with in our care services. The research we undertake is vital to improving the care we deliver and informing the knowledge that we share in our education activities. **Improving Care** is the focus for all our research.



Artist's impression of the main entrance to the LOROS Professional Development Centre



# LOROS

Hospice Care for Leicester, Leicestershire & Rutland

**loros.co.uk**

Registered Charity No: 506120

Being there for you  
and your family

## Wendy Gamble Newcomer Impact Award



Wendy Gamble, Research Manager at LOROS, won the award for “Newcomer Impact” at the Clinical Research Network East Midlands Research Awards for 2016 – 2017.

Wendy joined LOROS in May 2016 and took up a new post as the research manager for the hospice. She works alongside Professor Christina Faull in managing and delivering the research portfolio at LOROS and since starting in post has been instrumental in developing and managing the research team. She has quickly developed relationships, both internally and externally, which has led to the development of a good infrastructure to deliver studies safely and effectively.

Wendy has made an enormous and pivotal contribution in moving the service forward, she has recruited and trained the first research nurses at LOROS who are thriving under her leadership and encouragement.

Wendy is an amazing resource not only for LOROS but for the development of research in palliative care research across the East Midlands and nationally. She provides invaluable expert advice about governance and operational processes and advises on how protocols and associated documents could be strengthened to academic researchers who approach LOROS to develop collaborative projects. This has led to successful Sponsor and HRA approvals processes and minimization of risk as well as enhancing the quality of the research. Moreover it has allowed LOROS to continue to develop an eclectic breadth of research beyond the traditional clinical trials to support the evidence for all aspects of the care for patients with advanced illness.

Examples of this are our collaborations with archaeology and with conversation analysts.

Wendy is also working with the CRN East Midlands to share knowledge and experience to enable other hospices and palliative and end of life care centres to participate in research.

Wendy says “I have very much enjoyed my first year as the research manager at LOROS. It is a very special organisation and I’m very proud of the work we do here. Research is important because all care should be based on evidence and evidence is gained by doing good quality research. I believe that everyone receiving palliative and end of life care should have the opportunity to participate in research if they wish to.

I would like to thank Christina and the research team for their unstinting support and everyone within the organisation for their welcome, and for their support in our attempts to “elevate” research at LOROS, this includes patients and their families as well as staff.

The CRN who have also been very supportive in assisting with the provision of the infrastructure to enable us to be so successful during our first year.

I believe that this award is recognition of the work that the research team do here at LOROS and I am delighted to have won it. I would like to dedicate the award to Idi Nukis who sadly died in April. Idi was our research administrator and made a great contribution to the team, the award sits, quite rightly, on her desk, we all miss her very much.”

A few members of the LOROS Research Team

Left to right Naomi Seaton, Christina Faull, Wendy Gamble & Jo Potts



# The Prognosis in Palliative Care Study: PIPS2

It has been almost eight months since the new research nurse roles were created at LOROS funded by the East Midlands Clinical Research Network.

Registered Nurses Naomi Seaton and Jo Potts have shared the role of Research Nurse working predominantly on the Prognosis in Palliative Care Study (PIPS2), a portfolio study funded by the National Institute for Health Research and led by Professor Paddy Stone, University College London.

As the PIPS2 study aims to validate a tool for estimating prognosis and to compare it's predictions with those of clinicians, Jo and Naomi have relied on the support of nurses and doctors within the in-patient unit to be able to successfully recruit patients and obtain the data required for the research. The busy nature of the in-patient Palliative Care Unit and the time pressures this brings its nurses and doctors has provided the greatest challenge in the collection of data for the research.



However despite this, staff on the in-patient unit have been supportive of the research nurses and the introduction of a research study has been generally well received.

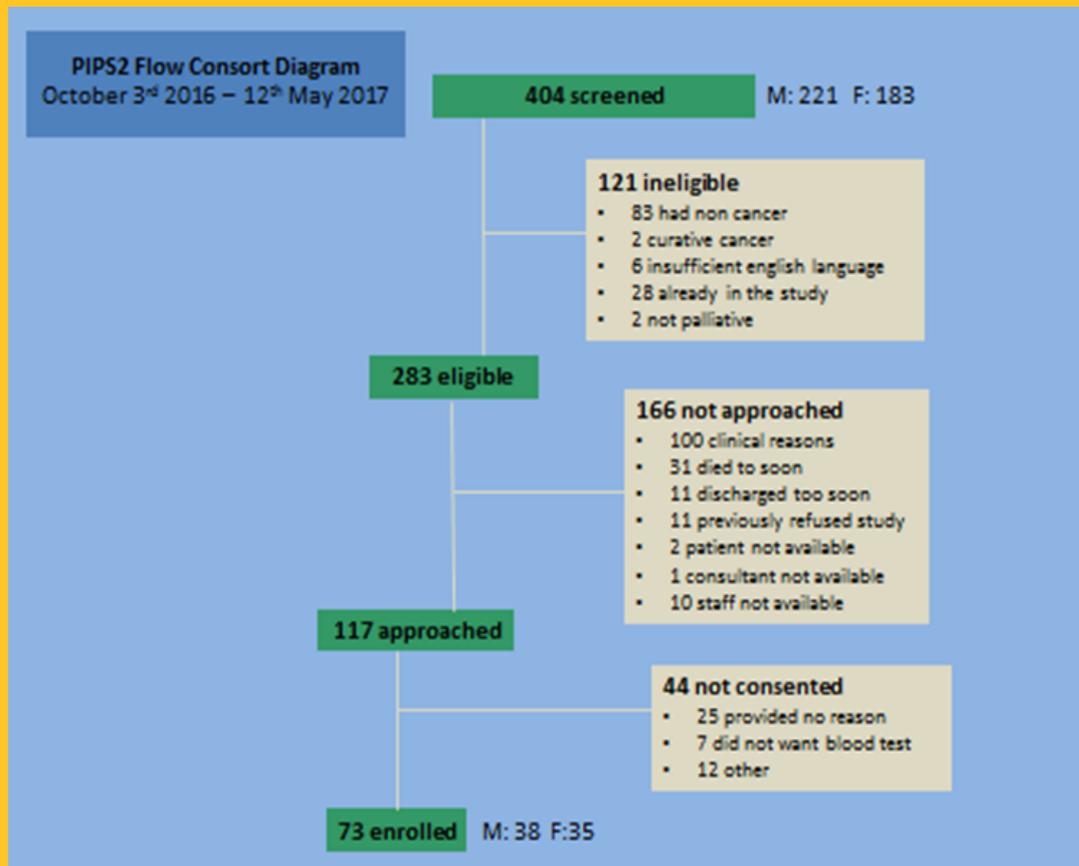
A sponsor monitoring visit on the 11<sup>th</sup> January of this year was very positive and showed no areas for concern. Recruitment commenced at LOROS on 3<sup>rd</sup> October 2016, with the target of recruiting 36 patients over a three year period. However, as of May 2017, the recruitment figure stands at 73 patients and continues to exceed expectations.



The Research Team would like to thank all the patients that have taken part and all the staff members who have helped to support us with this study. We will be continuing with the study for a little while longer and look forward to your continued support.

Our hospice inpatient screening and patient recruitment pathway is shown below.

A big thank you to all patients who have contributed to the project during their stay on the ward at LOROS.



## Managing Medicines



People approaching the end of life are likely to be older, to have a number of health problems and to be increasingly frail. During the last year of life they are likely to spend most of their time being cared for at home. This means that they, and their family and friends who support them, need to manage the medicines they are taking.

This often involves a large number of different drugs. Different medicines may need to be taken at different times of day.



Updates can be found at:

[https://www.researchgate.net/profile/Eleanor\\_Wilson2](https://www.researchgate.net/profile/Eleanor_Wilson2)

Some medicines may be intended to be taken only when they are required, and some of the medications involved may be strong and have potentially adverse side effects. This is a big responsibility to take on. This research study will explore how patients, their family members and friends who act as carers manage the medicines that are prescribed for them. We also want to find out about the support they receive from professionals involved in providing care.

The research is being carried out in three separate strands. The first strand will involve interviewing 20 bereaved family and friend carers and 20 healthcare professionals about their experiences of managing medicines during the last months of a patient's life.

The second strand will develop up to 20 family-centred case studies. These will consist of interviews with patients, their family and friend carers and any professionals whom they choose to nominate. We will also carry out observations of medication-related interactions between patients, their carers and healthcare professionals.

The final strand will bring together research participants plus other stakeholders, such as representatives of patient and carer groups, academics, educators and healthcare professionals, for a workshop to discuss the findings and make recommendations for how to bring these into practice. The study plans to include both patients who are receiving specialist palliative care and those who are not. It also aims to include patients from under-served groups, such as people from black, Asian and minority ethnic groups, people with severe mental health problems, people who are economically disadvantaged or with an illness other than cancer.

The research is taking place in the cities and counties of Nottingham and Leicester, and LOROS is one of the recruitment sites. The study is led by Dr Kristian Pollock at the University of Nottingham; please do get in touch with her if you would like to know more.



Dr Kristian Pollock

## Thinking Ahead: Complexities of Resuscitation Decisions with Diverse Communities in Leicestershire



Dr Zoebia Islam

With collaboration from University of Leicester Lucy Taylor (IBSc Medical Student), Dr Helen Eborall, Christina Faull and I have been busy undertaking 'Thinking Ahead' - a study which aims to identify things that can help doctors and nurses, when discussing deterioration and decisions about cardiopulmonary resuscitation, with patients with advanced illness and their families, especially those from minority ethnic communities.

**Why such a study?** Advance care planning (ACP) supports people who are seriously ill to be cared for in the way, and in the place that they prefer. However, evidence suggests there are lower levels of ACP in people from Black, Asian and Minority Ethnic (BAME) communities.



BAME groups are also more likely to desire invasive medical interventions, regardless of prognosis and impact on quality of life. Little is known about how the model of resuscitation decision-making fits with the social, cultural and religious values and beliefs of BAME groups. Evidence also suggests that health care professionals (HCPs) report a lack of confidence in having culturally appropriate discussions with BAME patients and their families.

There are two phases to this study. Phase one includes, thematic analysis of qualitative semi-structured interviews with HCPs across primary, secondary and tertiary care in Leicester, including GPs, hospital doctors and nurses. Findings from which have informed the development of Q methodology workshops conducted in phase two of the research project. Here public participants ranked 49 statements from those they most agreed to those they most disagreed with. They were then asked to explain their choices in a brief one to one interview.

### **What have we found out?**

Interviews and analysis is still ongoing, but preliminary findings from the interviews have highlighted the complexity of having such discussions. There was an emphasis on the significance of building rapport, the timing of discussions and navigating communication barriers. Barriers to decision-making included: patients' and their families understanding of both prognosis and resuscitation; differing values amongst generations of migrants. Professionals struggled with how to find a balance between acting in a non-discriminatory way whilst respecting cultural differences. The majority of HCPs highlight the need for further training.

We continue to receive a tremendous amount of support for the need for this study from HCPs and members of the public and will update you with its progress.

## Hot News



Congratulations to Lucy Taylor on achieving a well deserved First in BSc Medical Research (intercalated) (Hons) for her work on this project.

In this feature we speak to  
Professor Christina Faull

Consultant in Palliative Medicine. LOROS  
Lead for Research and Medical Lead for  
Education.

## 60 Seconds With...



### **What my role aims to do:**

*I lead the Research Team at LOROS. I am also the co-lead for palliative care research in the East Midlands working with Dr Andrew Wilcock who's based at Nottingham. I aim to develop research at LOROS and in palliative care more broadly so that patients and families and staff can have the opportunity to contribute to research to improve care and outcomes for patients and their families.*

*I am also responsible for helping doctors training in palliative medicine in Leicester, Kettering and Northampton to gain the competences in research that they need to be good Consultants and develop excellent services in the future.*

### **Best job:**

This one of course! Although I do enjoy my volunteering job at Northampton Homeless Night shelter too.

### **Worst job:**

*Strawberry picking! The train fare cost more than I earned all day.*

### **Favourite place to live:**

*By the Sea.*

### **Motto or Personal Mantra:**

Don't tell me I can't!

### **I'm happiest when:**

*Reading in the sunshine with the children laughing (and not bickering.)*

### **What I fear most:**

Similar to any parent I expect.

### **I'm proudest of:**

My Husband's skills and resilience in Leadership in the NHS.

For me personally it must be the publication of my first textbook which proved my English Teacher wrong!

### **Favourite sports or pastimes:**

I tend to move on to new things frequently. At the moment it's Yoga.

### **The Top 3 Highlights of my Life:**

So many to pick from....

A year in New Zealand as a junior doctor.

Two amazing boys.

27 years together and still enjoying the adventures.

### **People would be surprised to know:**

I can reel off about 20 'what do you call an elephant' ..... and other word play jokes.

### **If I could do it all over again, I would:**

Focus more on enjoying the journey and less getting to the destination.

### **Pet peeves:**

'Reply all' emails clogging up the daily inbox.  
False humility.

### **Favourite song, movie, book, or comedian:**

Out of Africa & Peter Kaye

### **Favourite Vehicle:**

A private jet..... never tried it but it looks such fun. No doubt I'd worry about the environment too much to be that indulgent though!

### **Before I die, I would like to:**

Know I had made others happy.

Travel a lot more.

Discover other talents.... I've been a doctor a long time and it's nearly time to do something else.

# Continuing Bonds and Dying Matters Awareness week

## 8<sup>th</sup> - 14<sup>th</sup> May

Leicester Cathedral welcomed to their brand new display boards an exhibition of archaeological materials related to LOROS and University of Bradford Continuing Bonds collaboration.

The exhibits aimed to stimulate people to think about death, bereavement, dying and living and used the 2017 Dying Matters theme 'What can you do?' to seek interaction with the exhibition from those visiting the cathedral and looking at the exhibition. Some very interesting comments were made on the 'post-it notes' and in the feedback

The Leicester Cathedral staff felt that the exhibition was very well received and an important part of their role. We are most grateful for their support and enthusiasm for this project and especially to Alison Adams the Deputy Dean. Alison has worked with us before in Dying Matters when we explored Death &

Legacy drawing on the recent discovery of Richard III. You can see Alison's talk about spiritual care related to the discovery of Richard III here <http://www.loros.co.uk/education-training-research/research/dying-matters-awareness-at-loros/>.



Continuing Bonds research workshops at De Montfort University and LOROS are seeking participants to come and share their thoughts about death, dying and bereavement in response to archaeological materials.

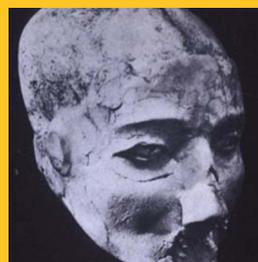
Contact [ContinuingBonds@bradford.ac.uk](mailto:ContinuingBonds@bradford.ac.uk) if you are interested in finding out more about the project or in participating in a workshop.



Some of the comments on post-it notes:

**“Talk to people before they die not about them after they’re dead”**

**“Make sure they have written down their wishes for the funeral”**



Jericho, plastered skull  
Kenyon archive, UCL

This keepsake contains a braided lock of hair.





East Midlands Research and Audit	1.30pm to 5.30pm  Lunch @ 1.00pm	21st September 2017	Professional Development Centre LOROS Hospice
Hospice UK National Conference	Leading Learning and Innovations	22nd—24th November 2017	Liverpool ACC
National Palliative Care Congress		March 2018	BIC, Bournemouth

## Is this the year that you want to get involved in research?

We can support you through a bursary of up to £1,000

### You might want:

- To attend a conference
- To go on a research training course
- Funding to backfill your time so that you can develop an idea or project
- Fees for a research qualification (e.g. MSc dissertation; OU module)
- 

### What you need to do:

- Discuss your ideas with your Line Manger and Christina Faull or Zoebia Islam
- Write a short application of no more than 1,000 words describing the purpose of the bursary. We want to know the value of the intended work; how it will improve your practice and the impact it will have on LOROS and the care of patients and families.
- The application will need to be supported, in writing, by your Line Manager and Head of Department.

Send your application by email together with the supporting statements to: [research@loros.co.uk](mailto:research@loros.co.uk)



**This is open to all staff at LOROS.**

## Continuing Bonds

### Archaeology meets End of Life Care

Are you a healthcare professional or student interested in exploring new ways of talking about death, dying and bereavement?



We are seeking healthcare students and qualified staff who would be interested in participating in a study to explore how discussions about death and dying in the past can open up conversations about these emotive topics in the present. Attending 1hr interactive workshops and responding to case studies, you will be asked to share your views with follow up feedback a few months later. You can attend one or more workshops in Bradford or Leicester.

**Next Workshop: 19th September 2017**

Contact [ContinuingBonds@bradford.ac.uk](mailto:ContinuingBonds@bradford.ac.uk)