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Patient Recruitment at LOROS Gets the Support of Two Research Nurses

We hope everyone at the Hospice will join us in welcoming two new faces to the research team...

Jo Potts and Naomi Seaton joined us in September, job sharing in the new role of Research Nurse at the Hospice. The posts are being funded by the Clinical Research Network (CRN) in the East Midlands, until March 2017, and both Jo and Naomi have a busy few months ahead of them.

As Research Nurses, their role is key to ensuring that patients are fully informed about research studies underway at the Hospice, and what participation will mean for them (including potential risks and benefits), before supporting the consenting process. Their role is also central to maintaining study data, and ensuring that members of the nursing staff and clinical teams are kept well-informed about new studies taking place.

Jo and Naomi both started at LOROS as nurses on the inpatient ward; Jo in 1988, and Naomi over ten years ago.

In 2004, Jo spent time working as a nurse in the Community, returning to LOROS in 2011. Since 2015, she has worked in the Day

Therapy Unit, helping to develop services for patients and carrying out audits. Jo now works three days a week on the Day Therapy Unit and two days a week with the research team.

In 2004, Naomi undertook a secondment as a Research Nurse at Hayward House specialist palliative care unit at the Nottingham City Hospital. More recently, to accommodate a change in personal circumstances, she has worked as a bank nurse on the Day Therapy Unit at LOROS, working closely with the CNS teams, outpatient clinics and therapists.

The first research project Jo and Naomi will be involved in is The Prognosis in Palliative Care Study II (PiPS2). This project is being carried out in 56 areas across the country and is looking to recruit 1361 patients. Initially, Jo and Naomi will be recruiting patients from the In Patient Unit for the study, before rolling it out across Day Therapy and Out Patients.

You can read more about the PiPS2 study on page 5.

Both Jo and Naomi are excited to be joining the Research Team and are happy for you to approach them if you would like to discuss, or have any questions about the PiPS2 study.

Jo says:

As a nurse I have always been aware of the need for practise to be evidence based but have not had the opportunity to help with evidencing it. Since working in Day Therapy, the Team have been asked to help recruit patients for ACTION research which made me start to think about how I could help become more involved in research.

This is my first experience of research, I am looking forward to starting and look forward to working with other members of the multi-disciplinary team to help assist with this research.

Naomi says:

During my secondment as a Research Nurse, working at Hayward House, the team carried out research into the relief of symptoms. During this time, I gained experience in recruiting patients from oncology clinics, the hospice, and its day therapy unit. I spent time with patients explaining the nature of the studies and supporting them throughout the research.

I can see the need for continued learning and progression in all aspects of palliative care but I also appreciate the sensitive nature of the palliative care setting and the challenges this can bring.



Jo Potts



Naomi Seaton

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LOROS

Hospice Care for Leicester, Leicestershire & Rutland

Being there for you
and your family

We're introducing a new feature in this edition:

'60 Seconds With...' gives you the opportunity to get to know a little bit more about some of the people linked to research at LOROS.

Let us know if there is someone particular you would like us to include!

In this edition we feature Hannah Finch, who started work as a Research Delivery Manager within the Clinical Research Network (CRN): East Midlands, in September 2016. Prior to this, from June 2008, Hannah was a Senior Research Management & Governance Manager, a post she held at the Network.

LOROS greatly values its links with the CRN: East Midlands, which recognises that the traditional landscape of NHS providers being the setting for delivering research is changing. The CRN is keen to offer the opportunity of clinical research to patients outside the 'traditional' setting.

2016/17 sees the Network working closely with LOROS to develop their capacity to deliver Portfolio research, and is doing this in a number of ways. Both parties hope that this relationship will continue to strengthen over the years to come.

What my role aims to do:

To make sure as many patients as possible are offered the opportunity to take part in NIHR research. There are 3 main functions to my role. Firstly I am a member of the Leadership team of the CRN: East Midlands, in this capacity I support the Chief Operating Officer and Clinical Director of the Network to manage network business and am responsible for research being delivered across the region. Secondly I am a 'Link' manager; this role involves me building a strong relationship with specific partner organisations, to support them in utilising their CRN budget and in effectively delivering NIHR Portfolio Research. Finally, I am the Research Delivery Manager for a number of specialties (Cancer, Children's, Genetics, Haematology and Reproductive Health & Childbirth). This means I maintain a management oversight of research operations in these specialties, and alongside the Network Specialty Lead, I lead the Networks strategic direction for these areas.

What I like best about working for the NIHR Clinical Research Network:

As we cover a wide geographic footprint, and have links with many NHS and non-NHS healthcare providers, I have to say I like the variety of my work, and the many people I meet who are passionate about clinical research!

Best job:

This is it!



60 Seconds With...

Worst job:

Working in a University library – those who know me will be surprised I could stay quiet for long periods of time!

Favourite place to live:

Wherever my family are, although I'd love to live by the sea (funny then that I live in land-locked Derby).

Motto or Personal Mantra:

This girl can!

I'm happiest when:

Two 'happiest when' scenarios: -

- In a field, listening to live music, with a drink in hand (possibly dancing like no-one is watching)
- Being with my children

One day these may merge into one, and the boys can buy me an overpriced pint at a festival!

What I fear most:

I have no fear.

I'm proudest of:

Completing the Yorkshire 3 peaks challenge within time, and in terrible weather conditions.

Favourite sports or pastimes:

I love walking, running and swimming. Listening to music and laughing with my friends and family.

The Top 3 Highlights of my Life:

1. Yorkshire 3 Peaks challenge
2. Running 10k
3. My children

People would be surprised to know:

1. I have met an odd trio of celebrities (Robbie Williams, Jack Black and Chris Moyles (not really a celeb and I was actually too star struck to speak to him, but I stood next to him at the bar for a good 5 minutes)
2. I don't like coins
3. Can't think of a third, I'm a bit of an open book!

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

Follow my teenage ambition to act and have singing lessons.

Pet peeves:

People who only focus on the problem, and not the potential solution.

Favourite song, movie, book, or comedian:

Song: Love an eclectic mix of music, couldn't possibly choose one song

Movie: I don't actually watch many movies, but I do love things that make me laugh; and action movies like Star Wars, James Bond, and Lord of the Rings.

Favourite Vehicle:

They just get you from A to B

Before I die, I would like to:

Travel and see more of the world.

Zoebia Islam returns from maternity leave and shares her plans for new research...

In October, the research team welcomed Zoebia Islam back from maternity leave, and were keen to hear her plans to develop new research ideas in the areas of Black, Asian and Minority Ethnic (BAME) communities and the transition of children to adult hospices.

Zoebia tells us 'I am glad to be back to work at LOROS and using my experience, knowledge and understanding of research to develop much needed work in the areas of: 'Black, Asian and Minority Ethnic (BAME) communities' experiences of advanced care planning. Particularly in understanding how health care professionals can support patients

from BAME communities and their families in planning their care in the last year of life. I am also keen to undertake work exploring young people's experiences of service transition between children's and adult Hospice care services. Such work is needed to ensure services meet these young people's needs in every stage of their lives.'

Zoebia is a Sociologist by background and has a passion for research particularly in the areas of ethnicity and disadvantage. Before joining LOROS, Zoebia was the Heart of England Hub Manager for the Mental Health Research Network and a Senior Research Fellow at Birmingham and Solihull Mental Health Foundation Trust (BSMHFT).

Zoebia has been involved in a number of innovative projects at the University of Warwick's Medical School and BSMHFT, in the areas of Mental health. This includes: exploring service user and carer perspectives in relation to transition from Child to Adult Mental health services (TRACK Study, SDO Funded) and more recently Transitioning young care-leavers with mental health needs

(LYNC study, PDG NIHR funded). As well as leading to numerous publications and replication of study in both Ireland (ITRACK study) and now several EU countries (Milestone project), TRACK led to a major focus on transition among policy makers and providers in England.

Zoebia has also managed a programme of research studies exploring the appropriateness of Early Intervention Services in Psychosis for Black and Minority Ethnic (BME) communities (ENRICH programme, NIHR Funded). The findings of this programme of work were recently disseminated via publications and a theatre production entitled 'CRACKED' (click [here](#) to see some recent publications).



Thinking Ahead... & Supporting New Opportunities

Hi, my name is Lucy Taylor and I'll be joining LOROS for the forthcoming year to take part in a research project being led by Dr Zoebia Islam.

The project is called 'Thinking Ahead' and aims to see how we

can improve palliative care services for ethnic minority groups, particularly focusing on making decisions about cardiopulmonary resuscitation.

Little is known about how current palliative care practices 'fit' with the social, cultural and religious values of diverse communities, but we do know that patients from black and minority ethnic (BAME) groups access palliative care less and are more likely to die in hospital. Healthcare professionals say that they don't feel confident broaching the subject of deterioration, dying and shared decision-making with patients and their families from ethnic minority communities, but there is very little published research about this.

Our project aims to explore these issues, which will hopefully feed into a larger project, along with the development of an educational resource for healthcare professionals.

There will be two parts to the project: we're going to be interviewing healthcare professionals about their experiences, and carrying out workshops with members of the public. During the workshops, participants will rank statements relating to deciding if they'd



want to be resuscitated if their hearts stopped beating based on the importance of the statements to their beliefs.

My work on the project will form my intercalated degree in Medical Research, which I am doing between my 3rd and 4th year of medical school at the University of Leicester. This is an opportunity to gain an additional degree in an area of my choice. I will be supervised throughout the project by Professor Christina Faull.

Leicester is unique in offering the Medical Research degree, which allows me to spend the whole year on a project rather than a term.

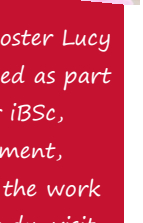
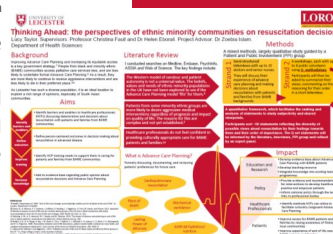
I've also recently begun working as a Bank Healthcare Assistant at LOROS, so I will become a familiar face at the Hospice!

I'd like to specialise in Palliative Medicine and continue to have a research element to my career, so I'm really looking forward to spending this year focusing on my interests and gaining experience.

I feel lucky to have the opportunity to be able to do this at LOROS, where I've received a huge amount of support and encouragement already. It feels lovely to be part of such an inspiring organisation.

To take part in the interviews for Thinking Ahead, or to request an information leaflet, please email/phone: research@loros.co.uk 0116 231 8498

To see a poster Lucy has designed as part of her iBSc, assessment, outlining the work of the study, visit our website [here](#).





From left: Nicole Challacombe, Margaret Beattie and Helen Holland, LOROS Physiotherapists

Introducing a New Journal Club...

Margaret Beattie, Physiotherapist

In August 2016, I completed literature search training in the LOROS Library. Here I acquired many new skills and refreshed some older skills, which I hadn't used for a while! It was a very productive time, to refresh my knowledge and interest in current research available. I really enjoyed the training and it gave me an insight into what is available to us, here at LOROS. As we always strive to provide evidence based treatments, this training reminded me yet again, of the importance of research and ultimately evidence based practise.

The training led me to having the idea of starting a Journal Club within the Physiotherapy team....I discussed it with our Lead Physiotherapist, Hannah Poulton, who felt this would be beneficial, and was happy for me to organise the sessions.

Our first session took place on 5th October 2016. The article chosen evaluated a Physiotherapy-led, non-pharmacological breathlessness programme for patients with intrathoracic malignancy. This was chosen because the team are currently looking at the service we provide to our patients who suffer with breathlessness. We are also looking at different techniques and strategies on how we can improve their breathlessness. As a group we discussed the content of the article. We analysed the study, treatment, results and findings and talked about whether there would be any benefit in transferring the study results into our practice, for our patients.

It was good to use the time for discussion and share our knowledge base to critique the article and to consider how it related to current practice. We agreed that, at present, we do not need to make changes to our current practice and that the service we are providing is using the most up to date evidence and treatments.

Being aware of research findings is important for our practice; it ensures we provide the best possible service to our patient group, one which is both relevant and evidence-based, helping to develop our service and organisation as a whole.

The journal club is to be held on the first Wednesday of every month, from 1-2pm in the Therapy Room, at LOROS Hospice. If any members of staff would like to come along, please get in touch with Maggie Beattie, Physiotherapist, or Hannah Poulton, Clinical Lead - Physiotherapist

New Conversation Analytic Findings in Medical Encounters

by Laura Jenkins, Research Fellow, Nottingham University

In our September 2015 edition, we included an article from Laura Jenkins, one of the researchers with the team from Nottingham University, working on the VERDIS study, which

looks at video-based research and training in decision making in end of life care.

settings. The study was based in seizure clinics, where practitioners are faced with a difficult challenge in differentiating between patients with epilepsy and psychogenic nonepileptic seizures (PNES), with over three quarters of patients with PNES initially (and inappropriately) started on treatment for epilepsy. Previous studies have demonstrated that experts in conversation analysis can identify linguistic and interactional features in transcripts and recordings of interviews with seizure patients that reliably distinguish between epilepsy and PNES. However this is only useful for practice if doctors themselves are able to identify and use these features in real time during everyday clinic consultations.

Laura and her colleagues delivered a one-day conversation analytic workshop to ten senior neurology trainees, who were trained in a different way of delivering history taking questions to allow patients more space to talk about their seizures. The doctors were then taught to recognise the linguistic and interactional differences in the conversation behaviour of patients with epilepsy and those with PNES. After the intervention, 55 initial outpatient visits were video and audio recorded, and immediately after talking to

patients the doctors completed a 12 item questionnaire. Doctors' mean responses to 6 of the 12 questions about linguistic and interactional observations differed significantly between the epilepsy and PNES groups. These items were able to correctly classify 81.8% of patients as having epilepsy or PNES. This study shows that a brief Conversation Analytic teaching intervention can enable neurologists to identify linguistic and interactional features supporting the differentiation of epilepsy and PNES as they take their patients' history in routine seizure clinic consultations, potentially improving diagnostic accuracy.

The on-going VERDIS project at LOROS has some similarities to the above study in that Laura and the team are using Conversation Analysis to look at how clinicians and patients talk about pain. Specifically, they are investigating how different clinician questions about the type and severity of pain people are experiencing are understood and answered. It is hoped that the findings will offer insights that can improve the accuracy of pain assessment and treatment decisions.

Laura's article can be accessed from [here](#).



Continued... Page 4

study conducted with Prof Markus Reuber and colleagues at the University of Sheffield in which they demonstrate how useful conversation analysis can be in medical

The Prognosis in Palliative Care Study

Christina Faull, Lead for Research

For the first time LOROS has been able to open as a research site as part of a national (NIHR portfolio) study.

Portfolio adopted studies, are studies that have been awarded funding in open competition with peer review process from the NHS or other national approved body such as a national charity. The portfolio adoption allows the NHS to support delivery of studies through the clinical research networks. Recruitment to studies by each regional network relates to their funding for subsequent years.

The Prognosis in Palliative Care study (PiPS) is lead by Professor Paddy Stone at the Marie Curie Palliative Care department at University College London and is funded by the National Institute for Health Research (NIHR) Health Technology Assessment programme. East Midlands Clinical Research Network funding has allowed two LOROS nurses to support this study. In their first four weeks they approached 25 patients on the ward and over 90% agreed to become participants, well above targets.

Helping patients understand their prognosis and identifying patients who are at risk of deteriorating and dying is an important part of achieving good end of life care and to ensure that patients are given opportunities to share their wishes and preferences for care and treatments. The NIHR called for research to improve the evidence base for

this crucial but complex area of clinical practice. PiPS aims to validate a tool for estimating prognosis and to compare it's predictions with those of clinicians. The study will involve 1361 patients and over 50 research sites in the UK.

The fact that over 90% of eligible patients are willing to participate indicates how important they think understanding prognosis is. It also tells us that many people want to contribute to research even at this very difficult time in their and their families lives. It's important to them that we provide this opportunity to contribute and for the evidence base and knowledge to grow in palliative care. At LOROS we are committed to making research part of our specialist services because patients want us to improve care for others.

*Contact the research team
if you would like more
information about PiPS2:*

research@loros.co.uk
0116 231 8498

Recognising Research Active Hospices

Wendy Gamble, Research Manager

Wendy Gamble, LOROS Research Manager, feeds back on her attendance at one of the two Research Active Hospices Stakeholder Meetings (hosted by Hospice UK), which she attended on 11th May 2016, at St Gemma's Hospice, Leeds.

The day started with a welcome and then an overview of hospice research in general and hopes for the future in terms of greater collaboration, increasing capacity and recognising the need for research to inform service delivery.

Opportunities and challenges were discussed, around areas of financial, ageing population, non-cancer / multi-morbidities and clinical and research workforce issues. The importance of

ensuring policy developments are based on good evidence was recognised.

The HRA process was discussed and it was acknowledged that there remain some areas, including that of how their processes relate to non-NHS organisations, that remain unclear, the group were informed that this is still "a work in progress" and it was agreed that national clarity is required on this issue.

The group were informed that the Department of Health intend to form a Palliative Care National Specialist Group which should then be recognised as a speciality in its own right and then the need for greater networking and support on a regional basis was discussed. Interactive maps were suggested and Hospice UK agreed that this was something that they may be able to assist with. It was thought that this would include a list of hospices with names and contact details of research leads and staff, with areas of interest / expertise detailed, which would encourage and facilitate networking and support.

There was feedback presented from a recent survey of stakeholders about research activity in hospices and a general discussion



about the future, including the need for investment by organisations to provide infrastructure to support and deliver research.

Hospice UK ended by confirming their commitment to support hospices in being research active and on the production of an action plan for the next 3 years.

A very interesting meeting and networking opportunity and those that I spoke to were very interested and impressed that LOROS have invested in research by appointing a research manager.

Good Clinical Practice Training for studies NOT involving Investigational Medicinal Products (GCP1) has Changed

From 1st July 2016 the current format of GCP1 training provided by University Hospitals of Leicester will be replaced by 4 bite sized Principles of Good Clinical Practice sessions. The following sessions will be offered:

1. Documentation, Data Management, Quality Assurance & Quality Control
2. Essential Documentation for the Conduct of a Research Study
3. Sample Management
4. Serious Adverse Event Reporting

You are only required to attend 1 session, (although researchers are welcome to attend more if they wish) and it is recommended that the chosen session is appropriate to your role in the research study. The training is valid for 3 years. It is recommended that the decision as to which sessions are appropriate for you to attend should be taken in collaboration with the Principal Investigator to best facilitate the research.

Each session will last for 45 minutes.

Further information regarding each session can be found on e-UHL, the R&I website (<http://www.leicestersresearch.nhs.uk/>) or by contacting:

RITraining@uhl-tr.nhs.uk

All 4 sessions MUST be booked via RITraining@uhl-tr.nhs.uk and NOT via e-UHL

Please be aware that there is **NO** change to GCP2 training for studies that **DO** involve Investigational Medicinal Products or Informed Consent for Research. These sessions can still be booked via e-UHL or RITraining@uhl-tr.nhs.uk

Monday 05 th December	GCP Bite-size	09:00 – 12:30	Seminar Room 1, CEC GGH Sessions 1, 2 & 3
Wednesday 07 th December	GCP 2	09:00 – 12:00	Professorial Seminar Room LGH
Wednesday 07 th December	Consent	12:30 – 14:45	Professorial Seminar Room LGH



University Hospitals of Leicester NHS Trust



LOROS Research Bursaries 2016

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

We can support you through a bursary of up to £1,500.

You might want:

- To present at, or 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)
- The Research Team will offer support in developing the work if you need some help.

What you need to do:

- Discuss your ideas with your Line Manager and Christina Faull
- Write an 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: idalizanukis@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.



What would it involve?

Attending a 1hr interactive workshop and responding to case studies around one of the themes listed below. You will be asked to share your views at the beginning and end of the workshop and with follow-up feedback a few months later. You can choose to attend one or more workshops.

Memorialisation & legacy

Ancestors

Images of the dead

Age & circumstance of death

Recruitment is underway for the study between researchers at the University of Bradford and LOROS/ University Hospitals Leicester...

Continuing Bonds: Exploring the Meaning & Legacy of Past & Contemporary Practice.

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 a 1hr interactive workshop and responding to case studies around one of the themes listed below. You will be asked to share your views at the beginning and end of the workshop and with follow-up feedback a few months later. You can choose to attend one or more workshops.

- Memorialisation and legacy
- Ancestors
- Images of the dead
- Age and circumstance of death

For more information, visit the University of Bradford website [here](http://www.bradford.ac.uk).

Email: ContinuingBonds@bradford.ac.uk

@CBondsStudy/#ContinuingBonds

For more information:
Email: ContinuingBonds@bradford.ac.uk
www.bradford.ac.uk/continuingbonds
@CBondsStudy/#ContinuingBonds



One final item of note...

In the May edition of our newsletter, we featured an article on Bariatric Patients and the Lymphoedema Clinic, which included a photograph of members of the Lymphoedema team.



A member of LOROS staff, Amanda Honnor, was incorrectly titled as 'Lymphoedema Nurse', when her role is actually that of 'Lymphoedema Sister' and we would like to apologise for this error.