

Research NEWS May 2014

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

This Issue:

Page 1	An Exciting Collaboration to Benefit Lymphoedema Care within the Community
Page 2	Meeting the Challenges: Black, Asian & Minority Ethnic Groups & BoLC Planning
Page 2	A few words from the Research Team...
Page 3-4	LOROS' Presence at the March 2014 Palliative Care Congress; Reflections from Harrogate
Page 5	How LOROS Plans to Take the Learning Forward...
Page 6	We Catch Up With Carolyn & Elaine...
Page 6	Taking a Hike for LOROS!
Page 7	Research into Practice: Feedback from the March 19th CPEP Conference
Page 7	Dates for the Diary

Issue N^o 5

An Exciting Collaboration to Benefit Lymphoedema Care within the Community

A few words from Professor Christine Moffatt, CBE

In April, the Lymphoedema team at LOROS were delighted to welcome a leading figure within the field of Clinical Nursing Research: Professor Christine Moffatt, CBE, will now be working collaboratively with LOROS and 3M Healthcare, on what is a new and exciting project aimed at improving community care for patients with lymphoedema....

I am delighted to be joining LOROS in a new project to develop a community nursing pathway for chronic oedema management. This is a project funded by the Knowledge

Transfer Partnership scheme and is a partnership with 3M Healthcare. This is an exciting project that will try to bridge the gap between patients seen within the specialist lymphoedema service and those requiring long term management in the community. The project will also seek to undertake local epidemiology of the magnitude of chronic oedema problems in Leicester. I hope this will be the start of a number of projects together and build on research that has already been conducted.

Benny Rossi, Head of Day Therapy & Community Services at LOROS, and Margaret Benson, Lymphoedema Manager, added that "The LOROS Lymphoedema team are very pleased to have the opportunity to participate in this project and work along side community colleagues and other specialists in the treatment of Lymphoedema to help develop this care pathway".



Main Picture (from Left to Right): Benny Rossi, Head of Day Therapy & Community Services, LOROS; Amanda Honnor, Lymphoedema Sister, LOROS; Christine Moffatt, CBE, Professor of Clinical Nursing Research, University of Nottingham; Angela Mears, Senior Marketing Executive, 3M Health Care Ltd; Margaret Benson, Lymphoedema Manager, LOROS. **Above Right:** Martin Nyomi, Charge Nurse within the Lymphoedema Team, applying a patient's dressing.



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LOROS

Hospice Care for Leicester, Leicestershire & Rutland

Being there for you
and your family



Chi Onwurah MP

Will act as Host at a Reception for Marie Curie Cancer Care to launch a new report on palliative and end of life care for Black, Asian and Minority Ethnic Groups in the UK

on 15th January 2013

and requests the pleasure of your company

Meeting the Challenges: Black, Asian & Minority Ethnic Groups & End of Life Care Planning ...By Zoebia Islam

The research team have been busy exploring issues around Black, Asian and Minority Ethnic groups (BAME) and end of life care planning.

As a result I was invited to attend a discussion group in September convened by Marie Curie to discuss the findings of the research report 'Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK' and the next steps.

These discussions have been included in Marie Curie's new policy report on

Palliative and end of life care for BAME Groups in the UK.

In addition, I was invited to attend the Parliamentary Reception on the 15th of January 2014 to launch this new policy report, on behalf of Chi Onwurah, MP for Newcastle upon Tyne Central, and Marie Curie Cancer Care.

It was great to be part of the development of such an important policy report, which highlights the need for our continued work in the development of research in this much neglected area.

The report referred to in Zoebia's article can be found at the following link:

<http://www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf>

The policy report is available from:

http://blog.mariecurie.org.uk/wp-content/uploads/2014/01/S487b_Next_steps_report.pdf

Pictured Left: Zoebia received an invite from Chi Onwurah MP back in December 2013. **Below:** Zoebia looks quite at home next to one of London's famous landmarks



A few words from the Research Team...

We're sure our readers will agree that this year already seems to be flying by!

This is the 5th edition of the Research Newsletter. We hope that it offers a flavour of how Research at LOROS is really starting to reach out into the wider palliative and end-of-life care communities; sharing good practice and promoting learning for the benefit of patient care, through our presence at key events, and as a result of our increasing collaborative work.

Findings from the research questionnaire that went out to all LOROS staff in October 2013, have now been collated into a report which highlights a universal endorsement of research as an important role for LOROS, both to improve practice and services and to benefit patients and their families. The full report was discussed by the LOROS Research Committee, who are working on the recommendations; key to that is keeping staff informed and getting more of you involved. If you would like to request a copy of the report, please contact: research@loros.co.uk

To help those who are interested in research to learn more about its basic principles and how it can help to inform practice, Zoebia has put together a **Beginners Guide to Research** study day, which will run on July 7th....please see our 'Dates for the Diary' section, or visit the Education section of the new-look LOROS website for more information: <http://www.loros.co.uk/education-training-research/>

In addition, take a look at our Research pages!

<http://www.loros.co.uk/education-training-research/research/>

We are frankly bowled over by how our web resource looks now and hope that you agree...and we'd love to hear your comments and suggestions.

We hope the 'pages' help both the public, patients, staff at LOROS, research collaborators and other interested parties know what is happening in research at LOROS, and we think that they play an important part in disseminating the findings

and improving the care for patients and their families.

We think it looks good but we need to know if the content is helpful enough and having the desired effects. We can monitor 'hits' but we'd like to know if you actually find it interesting and valuable. So please take a look and drop us an email.

We're also introducing a section on *Findings that might influence our practice...* So watch out for that hitting your inbox in coming weeks.

As always, we hope you will enjoy reading our latest news, and we welcome any comments, suggestions or feedback you may have for future issues.



The biennial Palliative Care Congress is a key event for palliative care professionals, attracting hundreds of delegates from the UK and abroad.

It is an opportunity to share learning and to look at some of the key issues faced by palliative care professionals.

This year, the congress took place from March 12th-14th in Harrogate, and the research team were delighted that LOROS had been successful in having 11 poster abstracts accepted, alongside an oral abstract for the VERDIS study, in conjunction with Ruth Parry and her team at Nottingham University.

Here are some reflections from those who attended the event, and thoughts on how this learning will be shared with staff, in order to further benefit patient care...

LOROS' Presence at the March 2014 Palliative Care Congress Reflections from Harrogate...

Main picture and inset: The Harrogate International Centre, venue for this year's Palliative Care Congress. Below: 11 posters were presented by LOROS at the conference; copies of these are available to view on the new-look LOROS website, at the link below:

<http://www.loros.co.uk/education-training-research/research/>

Kerry Blankley & Alison Pilsworth, Education Facilitators at LOROS

This was our first opportunity to attend such a conference and we were very excited (although a little apprehensive) to have a research poster on display entitled 'Influencing nurses communication style through a two-day interactive communication skills course'. Although it

felt very daunting when we were first approached by Professor Faull to submit an abstract, we had help, from both her and Idaliza Garner, in guiding us through the process and producing the abstract and the poster itself.

We were very proud to see the 11 posters the hospice had on display representing research work involving staff from LOROS. These provided an excellent opportunity to share our work and see what other teams were focusing on. All the abstracts from the event will be published in the BMJ Supportive and Palliative Care Journal. Our posters will also be displayed around the hospice on the research poster boards shortly.

In addition, more work involving LOROS was presented by Dr Ruth Parry, who has been conducting research with Nottingham University and our staff here. Some of the initial work was presented by Ruth; 'Views of hospice staff, patients and their significant others on video-recording consultations for use in research and teaching'. Ruth and the team will be continuing this research with us

here and more papers will undoubtedly follow.

The programme was varied over the 3 days, but gave us the opportunity to focus on areas that are particularly relevant to our education programme for staff both within the hospice and externally. These sessions included both clinical management and discussions relating to policy and service developments.

Overall, the congress provided an excellent learning and development opportunity which was clearly relevant to our practice. We left with lots of ideas and newly gained confidence from the opportunity to produce and share our poster. We would encourage others to be brave and share their work.

Continued...



Reflections from Harrogate, Continued...

*Dr Zahida Adam,
GP, Willowbrook Medical
Centre, Leicester*



As a local GP with a keen interest in Palliative and End of Life Care, I was very excited at the chance to attend the 10th Palliative Care Congress in Harrogate this year, and what an interesting three days it turned out to be! I had the opportunity to hear and meet with innovators in the field of Palliative Care as well as fellow non-palliative care specialists, learn of the research being carried out across the country and abroad and hear some lively and poignant debate about the future of Palliative Care

It was great to see so many posters exhibiting the work done at LOROS and I was pleased to contribute to representing Leicester with two further posters showcasing the work carried out by the Leicester City Clinical Commissioning Group (CCG).

With the help of Macmillan Cancer Support, LOROS and De Montfort University's Centre for the Promotion of Excellence in Palliative Care (CPEP), the CCG has in the last year

raised the profile of end of life care amongst GPs in the city with the appointment of myself and three other GP Mentors. Our posters highlighted the additional training that Leicester GPs have received to help them to identify patients who may be nearing the end of life and to create advance care plans for these patients. It was great to talk to colleagues and see their interest in how we have been improving end of life care in the local community. It appears that we are quite unique in having a dedicated End of Life Lead GP in every practice in the city and it was a real privilege to share our work and see what others were up to.

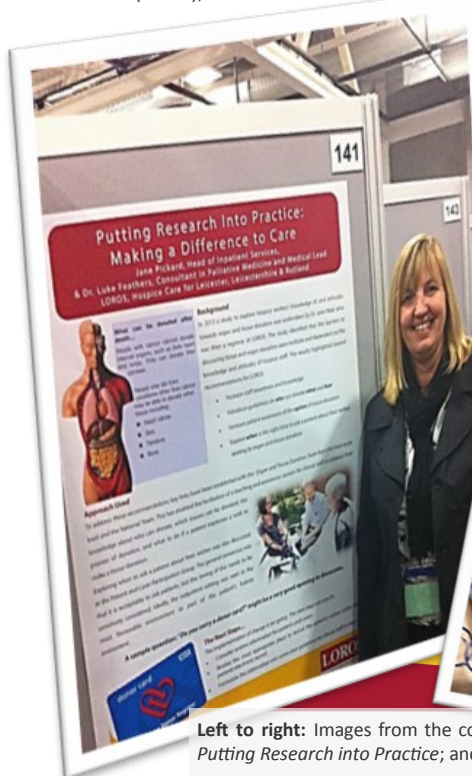
The free paper sessions were also a good opportunity to meet clinicians and learn about their work. It was very interesting to hear about research that Prof. Scott Murray's team in Edinburgh are doing looking at the disease trajectory of different types of illness. This concept, used as a tool in the Gold Standards Framework, is being used more frequently in general practice to help us to identify when a patient's chronic illness is progressing and whether they may be approaching the last year of life. I had the chance to speak to Prof. Murray about the differences between cancer, chronic disease and frailty with dementia, and where on this trajectory GPs can start preparing patients and enlisting the help of palliative care teams. It was encouraging to see how the qualitative evidence they had gathered backed what we were trying to achieve locally, that early care planning improved patient and carer experiences at the end of life.

A key message was the need for a basic level of palliative care understanding and training to reach doctors in all specialities, in hospital

and in primary care. LOROS's Prof. Christina Faulk pointed out, during one of the lively debates, that the General Medical Council places the responsibility for good end of life care on all doctors in the NHS and this was echoed by all. The majority of dying patients are cared for by non-palliative care specialists, GPs and hospital doctors, and the majority of patients do not die of cancer. As a generalist, it was very refreshing to see the importance of education and training being highlighted at the conference as well as an emphasis on the management of end stage heart failure and COPD through the dedicated master classes

There was heated discussion around the Neuberger Report and what a future pathway to assist in the last days of life might look like. Dr Gerard Corcoran from the Marie Curie Palliative Care Institute in Liverpool, argued that it was the core ethos of palliative care that had been misunderstood and poorly represented by the media and that raising awareness of dying and palliative care among the general public was important in ensuring that whatever emerges to replace the Liverpool Care Pathway isn't misused. Discussion around changing the way we talk about the end of life was very interesting, with the idea that we were "foregoing treatment" rather than "withholding treatment" being helpful. Also the idea that as health professionals we try to "recognise death" and not "diagnose" it, is a key message for GPs and nurses in the community to help patients make a steady, overlapping transition from curative to palliative treatment.

Overall I found the conference highly relevant to my every day work. It was a very inspiring few days, that left me buzzing with ideas and energy to bring back to my work with fellow GPs and patients..



Left to right: Images from the conference, including Jane Pickard with a poster she presented alongside Dr Luke Feathers, around *Putting Research into Practice*; and Prof Christina Faulk with her poster, around the *Withdrawal of Non-invasive Ventilation*

Reflections from Harrogate: How LOROS Plans to Take the Learning Forward...

With the Palliative Care Congress now over for two more years, and the posters successfully on display at the hospice, it is important that learning gained from the event is not lost. Here different members of the clinical and education teams at LOROS, share some particular moments of interest to them and tell us how they plan to take new ideas forward, for the benefit and development of future patient care....



Left to right: Dr Luke Feathers, Consultant in Palliative Medicine; Dr Laura Clipsham, Specialty Registrar; Dr Rosie Bronnert, Consultant in Palliative Medicine; Dr Mariam George, Specialty Registrar; Alison Pilsworth, Education Facilitator; Kerry Blankley, Education Facilitator; Jane Pickard, Head of Inpatient Services; Ruth Parry, Senior Research Fellow at Nottingham University; and Professor Christina Faull, Consultant in Palliative Medicine & Lead for Research at LOROS

- Following on from a session on **Breathlessness**, we realised the importance of the emotional response to breathlessness. We are now considering how we can promote and teach nurses, occupational therapists and physiotherapists about their role in the management of breathlessness.
- Watching a very moving and powerful play about assisted suicide "An instinct for kindness" – **made me understand more** about the impact of living with a disabling illness and also how challenging it is to go to Dignitas practically. It hasn't made me think assisted suicide is the answer though.
- "**Mindfulness**" as an approach – has stimulated several members of the team to read around this and get some training, so we can offer this approach to patients within the service
- We have already used some of the material around **Decision Making Theory**, for a training session with our community nurse specialist team. In particular, some of the thinking errors that we need to consider when helping patients undertake advance care planning. We have used some of the material to start an ethics **forum/discussion group** to make space to discuss some of our practical **ethical challenges** – e.g. the ethics of discharging patients against their will, who are not immanently dying, to allow admission of the next symptomatic patient.
- There was a useful discussion with a national lead around patient **outcome measurement**, including a project with the MND association on using patient outcomes to help stratify/direct level of intervention in a team with different levels of seniority.
- Highlights included a lecture on **cachexia** - which included definitions of pre-cachexia, cachexia and refractory cachexia. Explanation about the underlying causes and pathology as well as treatment options, including exercise, we could start using more proactively locally.
- Developing the **role of volunteers** to support the inpatient setting, and the different training available to develop this at LOROS, was of particular interest.
- The **Spirituality** talk - using the resources developed in the North West called "Opening the Spiritual Gate" and liaising with the chaplaincy team about programmes available to raise awareness of spirituality among clinical staff. Also understanding better the relationship and differences between **spiritual distress and religious distress**. The ultimate objective - to enable people to strengthen the inner person and minimize catastrophe.
- **Venous thromboembolism** - learning more about the second leading cause of death in Cancer patients and how the experience of having a VTE has a significant impact on the cancer journey and on daily living. While a 'blanket approach' (as in acute settings) is not needed or appropriate for all, this area of focus made me think that we should be more proactive in **risk assessment** e.g., prevalence higher in some cancers and during cancer treatment.

Contributions from: Dr Mariam George & Dr Clare Wilkins, Specialty Registrars, Kerry Blankley, Education Facilitator, Jane Pickard, Head of Inpatient Services, & Dr Luke Feathers, Medical Lead & Consultant in Palliative Medicine



Left to right: Ruth Parry, Senior Research at Nottingham University, with Professor Christina Faull, both of whom work collaboratively on the VERDIS study, for which Ruth gave an oral presentation; Dr Laura Clipsham, who successfully had two posters accepted; Dr Richard Kitchen, who is undertaking a two-year MEd with the LOROS/DMU Centre for the Promotion of Excellence in Palliative Care, CPEP, and who successfully had a poster abstract presented; and Alison Pilsworth, Kerry Blankley, and Jane Pickard, who also presented posters on behalf of LOROS.

We Catch Up With Carolyn & Elaine...

You will recall in the January Newsletter, we met with Carolyn Suffolk and Elaine Whitmore, HCA's based in Lymphoedema Outpatients at LOROS, who were set to take on the opportunity of studying the 10-week Evidence Based Practice module of the Foundation degree, with the aim of developing some of the key skills used within research.

Here we catch up with them to find out what they thought of the experience, and what they have taken away from it...

So, how did you find the experience of studying again...

Carolyn: I really enjoyed it and found I was looking forward to attending each week.

Elaine: To be truthful, I found it quite scary, but after the first session I was more relaxed. The group made us feel welcome and all sessions were interesting.

What did you think to the content of the course?

Carolyn: Really varied and very interesting, and everything was well explained.

Elaine: The evidence based practice element was very interesting; a subject I hadn't even thought about. And I found the pace of the course to be right for me too.

In what ways has the experience improved your confidence?

Carolyn: It has improved my confidence, and I now feel comfortable discussing evidenced based practice with my colleagues, as I understand it much more than I did before.

Elaine: It's improved my knowledge - made me think about research in a different light. I suppose I would be more confident to question certain articles and how we approach research.

Have you learnt anything in particular that has surprised you about research?

Carolyn: Quite a few things; in particular the different types of research - qualitative and quantitative. I was surprised how long the process of research takes, from start to finish, because of the need for ethical approval. Also, it was surprising how many people are

involved in setting a project up and getting it off the ground and how many more can then be involved as participants.

Elaine: I have learnt so much on ethics, bias, qualitative and quantitative research and critiquing articles. Also around how research can provide the evidence for better practice; when you're being trained to do a job, you don't always realise there is evidence to support your practice.

Have you had an opportunity to put any of the learning into practice yet?

Carolyn: Not yet, but I soon hope to!

Elaine: Not at the moment, but I would feel more confident about becoming involved.

Given the collaboration that is now underway between LOROS, Professor Christine Moffatt and 3M Healthcare, do you feel that these are exciting times for the Lymphoedema team at LOROS?

Carolyn: It is very exciting for the team, and I'm looking forward to being part of that research.

Elaine: Yes - though, I'm not sure, at this stage, how we are to be involved.

In what ways do you now hope to become involved with research?

Carolyn: The Lymphoedema team have been involved in different research projects before, which have needed support with data collection; I would be happy to be involved with this.

If you would like more information about any of the study days, learning events, accredited or short courses offered by LOROS, please

email the Education department: education@loros.co.uk

Phone: 0116 231 8455 or Visit:

<http://www.loros.co.uk/education-training-research/>



Carolyn Suffolk (left) and Elaine Whitmore

Elaine: I would be interested in supporting work around data collection - such as surveys or focus groups.

Looking back, do you have any advice to others who might be considering a course of study?

Carolyn: I would say have a go at the research module, if you are interested in research - you will learn a lot. To those who may be interested in the Foundation Degree, I think it would be well worth it as it would enhance your career greatly.

Elaine: I found the module very interesting. My advice is, if you don't want to do the full Foundation degree, why not consider just this module - it opens your eyes to how important research is!

Has the experience helped to whet your appetite for future learning?

Carolyn: Yes, it has...both Elaine and I would like to know more about other modules that are available. I also recently attended, and got a certificate for, Good Clinical Practice training, offered by the UHL at LOROS, and I found this a really useful follow on from the research module.

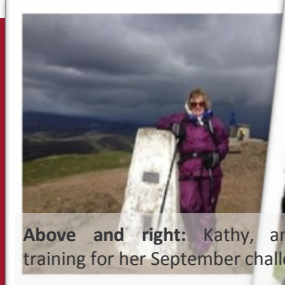
Elaine: Yes - both Carolyn and myself would consider more learning in the future. I also attended the GCP session and found the module had made it easier to understand what was covered in this; my understanding about research is a lot clearer now.



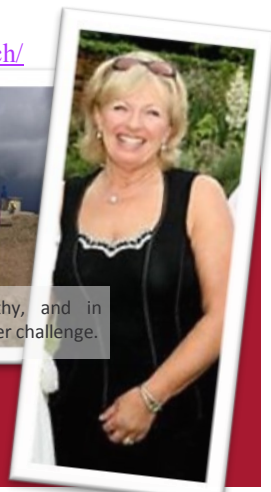
Taking a Hike for LOROS!

On a personal note, the research team would just like to take this opportunity to say how proud they are of Kathy Castleman.... Kathy is a LOROS Volunteer who has supported the research team for over a year.

She is gallantly taking on the LOROS Coast to Coast walk in September, which will see her tackle a 192 mile route over 13 days, to raise funds for LOROS. The challenge will take her through some of the best countryside in Britain, including the Lake District, the Yorkshire Dales and the remote North Yorkshire moors. Kathy is an invaluable member of the team, and we are confident she will take this challenge in her stride!



Above and right: Kathy, and in training for her September challenge.



Research into Practice:

Feedback from the March 19th CPEP Conference Aimed at Nurses, Health & Social Care Professionals with an interest in Palliative & End of Life Care

By Dr Lynn Furber, Senior Lecturer, De Montfort University

The DMU and LOROS Centre for Promotion of Excellence in Palliative Care (CPEP) held a conference entitled 'Research into Practice: A Conference for Nurses, Health and Social Care Professionals with an interest in Palliative and End of Life Care,' on the 19th March 2014 in the School of Nursing and Midwifery at De Montfort University.

The aim of the conference was to spread the word about palliative and end of life research being undertaken by nurses and allied health professionals in the region and the difference it is making to care.

Feedback was positive; *"Today has reassured that I want to be the best nurse I can be but more importantly it made me realise that it is possible and if I am determined enough I can get to where I want to be and be actively part of research."*

Professor Jayne Brown was delighted that the conference was a great success and expressed how wonderful it was to have so many colleagues from across the East Midlands coming together to present, discuss, debate and inspire one another on their journey in palliative care research.

Special thanks must be given to Macmillan Cancer Support who funded the event. Following on from this success we will be looking to promote further events in the future to generate

interest, research ideas and information exchange between colleagues with interest in palliative and end of life care and will of course keep you in touch with our plans.

See our Dates for the Diary section for details of a forthcoming CPEP Lecture, to be given by Prof. Irene Higginson, in November...



Main Picture (from Left to Right): Jayne Brown, Professor of Palliative Care, DMU; Jane Seymour, Sue Ryder Care Professor in Palliative & End of Life Studies, University of Nottingham; Karen Lord, Macmillan Clinical Academic Research Nurse, UHL; Dr Lynn Furber, Senior Lecturer, DMU. Above Right: Jayne Brown welcoming delegates to the conference.



CENTRE FOR THE PROMOTION OF EXCELLENCE IN PALLIATIVE CARE



Annual Lecture:

Centre for the Promotion of Excellence in Palliative Care (CPEP)

Hospices & Universities Working Together: Does it raise the game? Reflections from Creating the Cicely Saunders Institute

12th November 2014 (Evening) at De Montfort University (places are free)

CPEP's guest speaker will be Professor Irene Higginson, Director of the Cicely Saunders Institute.

Details have yet to be announced, but for further information, please contact Martyn Geary, Senior Lecturer for Adult Nursing: mgeary@dmu.ac.uk

A Beginners Guide to Research (Study Day)

7th July 2014, LOROS Hospice

A study day aimed at anyone with an interest in understanding the basic principles of research and how it is used to inform practice.

Topics include: • Understanding evidence based practice • Identifying problems that can occur • Developing techniques for gathering information • Basic evaluation of the existing evidence base • Exploring ethics • Presenting information to others

Cost: £25 (Students £15)

For further information please contact LOROS Education on:

0116 231 8455 or email: education@loros.co.uk

A Cup O' Learning & A Slice O' Cake

18th July 2014 (from 12:00 - 1:00pm)

Frizelle 1, LOROS Hospice

The third in our series of **free** lunchtime learning sessions will welcome Olivia Hill, who will be delivering a presentation around her project, which looked at perspectives in the UK and US on what specialist hospice nurses perceive to be 'excellent practice'

To reserve a place, please email: PaigeMurney@loros.co.uk

Leicestershire, Northamptonshire & Rutland (LNR)

Audit & Research Day

30th September 2014, 1:00 - 5:00pm

Frizelle 1, LOROS Hospice

This event is for palliative care doctors and is open to other professionals within Leicestershire, Northamptonshire & Rutland.

The programme includes presentations of local research and clinical audit projects. For more information, please contact

Professor Christina Faull: christinafaull@loros.co.uk

If you have an item of research news that you would like to share in the next edition, or would like to comment on

any articles in this issue, please contact:



idalizagarner@loros.co.uk