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Research Active Hospices: Why Bother?

Sarah Russell - Head of Research and Clinical Innovation at Hospice UK reflects on why hospices should be research active

For the 10th edition of the LOROS Research Newsletter, Sarah Russell has shared with us the vision for research active hospices. We want to say a huge 'thank you' to Sarah for her support and encouragement...

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Part of my role at Hospice UK is in response to the Commission into the Future of Hospice Care report <u>'Research in palliative care: can hospices afford not to be involved?'</u>

Despite the lack of funding for palliative care research (Higginson 2016) and need to develop further the research confidence and competency of hospice staff (Payne et al 2013), hospices have a key contribution to make to palliative and end of life care. For example, understanding the needs of an ageing population, complexity of need, multiple care settings, variation in care and financial constraints all point to the benefits to patients, their families and our communities for hospices to be research active.

Keogh (2013) argues that the best treatment is delivered by clinicians who are engaged in research and innovation. I agree to a certain extent - whether it is by being actively aware, engaged or indeed leading research. Research enables hospices to a) sustain or prove high quality care, b) understand the needs of those we care for, c) be an effective workforce and d) make a difference to care (Payne et al 2013). Research provides information to support negotiations with commissioners and purchasers of services as well as evidence of the cost-effectiveness of our care.

So what is Hospice UK's vision for research active hospices and where does LOROS fit in? Hospice UK's objective is to support hospices to be realistically research active. For example, from actively leading and taking part in research to being confident in evidenced based every day practice and policies. We are taking this forward through consultations, initial stakeholder meetings (11th May and 29th June) and agreeing an action plan. e.g.

- 1. Share and confirm the main challenges and current examples and solutions for hospice research activity.
- 2. Discuss/map out the detail of how to define a Research Active Hospice
- 3. Identify what support and collaborations hospices need to be research active from each other, local peer, research or governance networks, established forums and groups, education needs, the Health Research Authority, academic centres, Universities, Hospice UK and others.
- 4. Outline priorities for the next three years with Hospice UK summarizing and producing an action plan as an outcome.

LOROS is a great example of a research active hospice and has been generous in



sharing its experiences. The recent Research



I do believe that research is integral to hospice and palliative care. As Banerjee (2016) recently pointed out 'excellent healthcare has clinical research pulsing in its veins'. Combining clinical care and research is integral to all that we do. For example Farrar (2015) comments; 'working as a doctor made me a better researcher, but working as a researcher made me a better doctor too'. LOROS's example will help others as you combine care and research. I am very much looking forward to working together and with the rest of the hospice community as we share a vision for achievable, meaningful individual hospice research activity.

Sarah's role at Hospice UK is concerned with research activity, advance care planning, digital innovation, e-learning, care homes, outcomes and knowledge dissemination.

You can contact her via Twitter

<u>@learnhospice</u> or

<u>s.russell@hospiceuk.ora</u>



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Highlights from the 2016 Palliative Care Congress

The 11th Palliative Care Congress took place at the Scottish Exhibition Conference Centre Glasgow, over 3 days in March. Several staff from attended LOROS event, which attracts end of life care professionals from as far afield as New Zealand, India, Canada the United Arab Emirates (UAE).

The theme was 'Rediscovering Holism: the future for Palliative Care' and LOROS presented ten posters, as well as two oral presentations (delivered by Professor Christina Faull).

Here are some of the highlights from those who attended, starting with feedback from Hannah Poulton, Clinical Lead Physiotherapist...



Hannah Poulton, Clinical Lead Physiotherapist (centre), attended the conference with colleagues Helene Morgan, Nursing Team Leader (left); Tracey Hinde, Nursing Team Leader(2nd right); and Rachel Atkinson, Clinical Lead Occupational Therapist (far right)



I had the opportunity of attending this year's PCC along with colleagues from the Multidisciplinary Team. The sessions and speakers were excellent, and covered relevant topics such as: "Should Hospices have a gym?"; new advances in pain management; the work of cancer charities and goal setting within palliative care. To hear what other charities are achieving and developing was inspiring, and it also highlighted just how pro active and forward thinking LOROS is.

After listening to the talk on utilising a gym in the hospice, I was inspired to gather other evidence which suggests the benefits of having a gym, especially as some of our current Day Therapy patients have already expressed a wish to "engage in some form of exercise programme." Looking ahead I am hopeful that, with the future plans for development of Day Therapy, and increasing numbers of patients, a basic exercise class could be a possibility.

Another session I attended looked at creative writing and how patients have found this to be a therapeutic way of sharing thoughts and feelings in a safe environment. The study was undertaken over a 6 week period, amongst patients using Day Therapy Services. It got me thinking that this could be something which we implement as part of our own Day Therapy's "Creative sessions" offering another way to engage with our patients and for them to share their journey.

During the course of the conference, there were dedicated time slots to review posters of current research projects and to also look at displays, works of art and photographs, all

capturing the essence of what palliative care is. It was encouraging to see the research and studies being undertaken within palliative care.

One particular study explored the use of the Lung Volume Recruitment (LVR) Bag. The researcher was able to demonstrate the effectiveness of using this piece of equipment with a particular group of patients, and this has already enhanced our practice here at LOROS, as we have now invested in a supply of LVR bags, which we will start to trial with suitable patients. We hope that the LVR Bag will have a positive effect; preventing chest infections, helping patients take a deeper breath and putting them in control of this treatment.

There was a time for networking, generating and sharing ideas amongst colleagues and other professionals from different hospitals, hospices and community settings. This helped to highlight what is going well and what needs to be improved... feed back which we have shared in our own team meetings and also at the ACPOPC (Association of Chartered Physiotherapists in Oncology and Palliative care) meetings.

Overall, I thought the conference was inspiring and encouraging. To learn new ideas which we can put into practice at LOROS, to enhance the treatment and services we currently provide was so valuable. We also felt proud to be part of this conference, and to showcase the amazing work which LOROS already provides.

Highlights from the PCC Continued...

Highlights from the 2016 Palliative Care Congress (Continued...)

A huge congratulations to Dr Kathryn Lockwood, Specialty Registrar at LOROS, who was awarded a prize for her poster looking at 'Can a proactive approach improve palliative care input to medical admissions wards?', work undertaken with detailing Dr Laura Clipsham, Consultant in Palliative Medicine at the University Hospitals of Leicester. Here, Kathryn shares a few words about the project along with thoughts on the conference...



I attended the Congress to present a poster that I had written with Dr Laura Clipsham (Consultant in Palliative Medicine). It was a summary of development within the Hospital Palliative Care team at Leicester Royal Infirmary

The poster was entitled 'Can a Proactive Approach Improve Palliative Care Input to Medical Admissions Wards?' Dr Clipsham had instigated a change in the way patients with palliative care needs attending the Medical Admissions Unit (MAU) were

identified. Rather than wait for referrals, a Consultant or Registrar from the Palliative Care Team attend MAU each day to discuss with the medical and nursing team whether any patients who would benefit from Specialist Palliative Care input. The MAU is a short stay unit so some patients are only in for one or two days and the idea was that could be

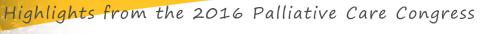
months later. We then compared the number of patients seen to a year previously to see whether the number referrals

The results showed a sustained three to four-fold increase in the number of patients accessing Specialist Palliative Care within MAU. The reason for referrals included symptom control, psychological support and future care planning. The patients had both malignant and non-malignant diseases. In some cases we provided advice to the MAU teams although in the majority we patients The data collected did not provide any way of assessing the benefit that patients get from the Palliative Care Team but we hope that seeing more patients early in their hospital stay is beneficial to them.

The Hospital Palliative Care Team have continued with this initiative since this evaluation and continue to review the service and how it is changing when they get involved with patients within their hospital stay and which patients they see.

different topics. Often I found it hard to choose which session, as several concurrent ones looked interesting. The posters were also very varied with contributions from many different centres. These made me think about new ways of working about ideas that could bring about positive change. This was my first attendance at the PCC, and it was nice to be part of a large LOROS contingent including those from the Enablement team and Nursing team. I am grateful for the funding from LOROS research bursary, which allowed me to attend.





(Continued...)

Our Congress Experience

Sister Tracey Hinde & Sister Helene Morgan

The 11th Palliative Care Congress in Glasgow 2016 provided us both with the opportunity to view posters, attend several informative sessions, and recognise similarities with other hospices and ideas which could be implemented to impact on patient care. The impact of this learning experience is something we want to share with the rest of our team.

Several master classes, plenaries, lectures and workshops incorporated new trends in pain control, assessments and evidence for new approaches for treatment of neuropathic pain in cancer patients. We gained an improved understanding of the evidence for the weak benefit of the use of Ketamine in individualised pain. Other session's, included spiritual wellbeing, creative writing, attitudes and preferences in palliative care.

It was evident that there are similarities of developing practice amongst Hospices across the United Kingdom. Latest advances in outcome measures (IPOS) centred on patients and their families concerns are extensively recognised in clinical treatment, care, audit, research and training. This is something that is soon to be implemented here at LOROS.

Many interesting sessions showed how Hospices are using evidence to promote good practice in palliative Care. The masterclass "Facilitating Hospices", sponsored by Marie Curie, highlighted to us the need for our nursing teams to become more engaged in research and how this could benefit patient care. Recognising the barriers and challenges this brings, we plan to redevelop a group, for nurses motivated to continually look at ways of improving nursing practice and patient care. By getting together on a regular basis to generate ideas and utilising the variety of skills, our vision is that the group will gradually take part in research studies that will be implemented to have a direct impact on patients and their families.

The fascinating workshop "death, dying and grief in the online universe" highlighted to us where death and technology meet, certain concerns and fears arise. Social networking sites, like Facebook are now a primary means of communication as it allows us to capture, store, and access words and images on an unimaginable scale. This can have profound implications for

living and dying; death and remembrance and the impact of the legacies we leave behind. Questions around our digital

remains are not something we had considered before. Maybe this is thought for the future.



Sister Helene Morgan (above) and Sister Tracey Hinde (right)

A full list of the abstracts from this year's PCC is available on the Palliative Medicine Journal website <u>here</u>



LOROS Welcomes a New Research Manager...

The research team continue to be busy with various areas of activity... One of them being the appointment of a brand new role... that of Research Manager. Wendy Gamble brings a wealth of skill and experience to the new post...and we are sure that you will join us in welcoming Wendy to LOROS.

My interest in research began in 1991 when I was working as a nurse at LOROS. I initially got involved with some data collection and then progressed to working on other research projects that were happening at LOROS at that time. I made the decision to progress my research career and took an opportunity to work as a research nurse, and later a research manager, firstly at University Hospitals of Leicester NHS Trust and latterly for the University of Leicester. For the last four years I have worked as the Research Governance Manager for the University which has been a

challenging and rewarding role and has enabled me to see research from "the other side".

I maintained my interest in Palliative Medicine and have always hoped that at some point I would be able to combine that with my interest and passion for research.

Research is an important area in all specialities as working practices should be based on evidence, and in order to produce this evidence good quality research needs to be undertaken.

I am delighted to have been offered the post of Research Manager at LOROS and will be working alongside the team to develop and deliver the research portfolio and I look forward to working collaboratively with other organisations to promote both LOROS and research to ensure that we are established and recognised as a centre of excellence for research and development in palliative, supportive and end of life care for the future.



Why I don't want to 'Join the Choir Invisible'

Idaliza Nukis, Research Administrator

each edition of the Research Newsletter, I have never written an article

now...but I want to share with our readers an important learning curve that recently happened for me.

In recent weeks, I have been working with Maggie Fay, Practice Educator, planning and preparing events for Dying Matters Awareness week. I sit opposite Maggie, and was listening to a conversation she was having with other members of the education team, about the reluctance people have of using the words 'death' and 'dying'. Maggie was citing the example of recent tabloid coverage of the many celebrity deaths we've had so far this year, many of whom have been described as having 'passed away' or other such euphemisms.

Despite editing I listened to what she had to say with interest - I'd never really thought about it until that point – but it was later that day that I realised for myself just how true Maggie's words were. I was busy in conversation with her about someone, and without thinking I said that they had "lost" their Mum at LOROS. Maggie looked up at me from behind her computer and said, "Oh...you mean she died here".

> Suddenly, my freeze-frame moment happened. It was almost as if a cartoon character had leapt up from my desk, smacked me in the face and pulled my hair... and I realised exactly what Maggie had been getting at earlier that day.

> Most of us find it so very difficult to use the words 'death', 'dead', 'dying'. It's almost as if in saying them, we are admitting to some dark secret; if we use the word 'death' too freely we will 'catch' it; or, as the children's stories warn, if we say the word 'Bogeyman' three times something nasty will appear.

My learning curve is that we have to revisit our relationship with these words.

When a baby's life begins, there is power in recognising that they are 'born' and rejoicing in the moment of their 'birth'.

At the end of my life, I don't want to 'pass on' quietly, 'slip away', become 'lost', 'cross over', 'check out', 'expire' or 'cease to be'. I certainly don't want to be remembered for 'joining the choir invisible'.

I hope that the loved ones I leave behind will award me some strength - recognising that I have 'died' and acknowledging that I have experienced my 'death'.

Working with Maggie, and involvement in Dying Matters Awareness Week, has taught me that Dying Matters, but that TALKING ABOUT DYING matters too...very much.

You can read more about Dying Matters Awareness week <u>here</u>.

Bariatric Patients & the Lymphoedema Clinic

Gill Swain, Lymphoedema Sister

The Lymphoedema Clinic has faced increasing concern regarding bariatric patients and their presenting challenges. This clinic, established in 1995, initially for patients with cancer related lymphoedema, has transitioned into currently seeing more non-cancer related lymphoedema patients than cancer related. A considerable number of these patients are obese or morbidly obese, often with multiple comorbidities posing consequential health and safety issues for the clinic resulting in the purchase of bariatric furniture/equipment. Risk assessments are required to mitigate moving and handling issues.

Patients failure to address their obesity which potentially impacts their response to Lymphoedema management was concerning. The Lymphoedema team introduced initiatives to address these problems which Dr Wilkins et al (2014) described in the Journal of Lymphoedema. Initiative one, was monthly group sessions for patients with a BMI of 40 or above with a Dietician and Lymphoedema HCA. Food calorific and fat content was discussed and portion sizes. Poor attendance led to these sessions being disbanded.

Secondly, a one stop Bariatric Lymphoedema Clinic was introduced for patients with a BMI 40 and above where a Lymphoedema Medical Consultant, Nurse Specialist and Dietician saw the patients. Information provided included Lymphoedema / Chronic Oedema management, good skin care advice and weight loss was required prior to consideration of compression therapies. An outcome tool was developed for the clinic patients. During the year long duration of the clinic, poor attendance and uptake of dietetic review was apparent. Due to so many patients having a BMI of 40 and above the clinic waiting list increased. The clinic stopped and all patients irrespective of their BMI were returned to the Nurse led Lymphoedema Clinic.

Subsequent concern among the team centred on whether the compression therapies would work for these patients.



Margaret Benson, Lymphoedema Services Manager; Gill Swain, Lymphoedema Sister; Amanda Honnor, Lymphoedema Nurse; Carolyn Suffolk, Lymphoedema HCA

> Staff anecdotally believed that these made little difference. The compression garments required had to be specifically made and were expensive. The justification for a Hospice / Charity, although part funded by the CCG's, still relies on charitable donations to cover the entire cost of the services provided and therefore paying for these garments was questioned. Obesity problems need addressing first and not by the Hospice. It was therefore agreed that unless patients with a BMI 40 and above had lymphoedematous changes compression would not be offered and they would be discharged back to the GP, having been referred to a dietician.

Wilkins C, Swain G, Cooke C (2014) Facing up to the obesity crisis: outcomes of a bariatric lymphoedema clinic. Journal of Lymphoedema 9 (2): 27-29.

A copy of the article, co-written by Gill, can be obtained from the Journal of Lymphoedema, here.

VERDIS-AHP

Video-Based Communication Research with Allied Health Professionals

Dr Wendy Archer, Research Fellow, Nottingham University

Over the coming weeks and months, a researcher from the University of Nottingham, Dr Wendy Archer, will be spending time at LOROS collecting data for a new research project which will involve analysis of video recordings of consultations and therapy sessions between physiotherapists and occupational therapists and their significant others.

Following on from the VERDIS Communication project (September 2013 Newsletter, Issue 3), the new VERDIS-AHP project aims to develop more knowledge about how specialist physiotherapists and occupational therapists communicate with hospice patients and their significant others through speech, touch and gesture to talk about sensitive issues and to make decisions together. This knowledge, alongside clips from the video-recordings, will be used to enhance training resources used in communication skills training.

Wendy has a background in applied linguistics (the scientific study of language) and has previously carried out research using audioand video-recordings and Conversation Analysis techniques in both healthcare and educational contexts. She is particularly interested in understanding how language is used in professional settings and how this



knowledge can be applied in developing specialist training materials for healthcare practitioners in a variety of medical settings.

After spending several years working in the UK and overseas as a University lecturer and teacher trainer, Wendy joined the team at the University of Nottingham in January 2016 to focus on her research work. She will work full-time on the VERDIS-AHP project for 36 months and will be a regular visitor to LOROS in the coming weeks and months. She is currently spending her time at LOROS working with Physiotherapists and Occupational Therapists in the Enablement team and will be meeting and talking with

various members of staff, patients and their significant others about the VERDIS-AHP study.

Funded by the National Institute for Health Research, the research is being led by Dr Ruth Parry (from the University of Nottingham). At LOROS, Prof. Christina Faull, Rachel Atkinson and Idaliza Nukis are also members of the research team.

If you would like to know more about this research, or to ask about participation, please contact:

wendy.archer@nottingham.ac.uk

Tel: 0115 823 0860

Continuing Bonds:

Exploring the Meaning & Legacy of Past & Contemporary Practice



You will recall in our last edition of the Research Newsletter, an article on a new 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 delighted to announce the start of the project which, during the next 28 months, will investigate how the past can help shape and inform contemporary healthcare practice, particularly around end of life care. Case studies from the past and from ethnographic sources will be used to

investigate whether they can help provide a new understanding, a different vocabulary, and might aid and facilitate those difficult conversations around death and dying.

For further information about the project, click here.

Project workshops will commence in October 2016.

If you are a healthcare professional or student and would like to be involved, please contact:

Christina Faull: research@loros.co.uk

LOROS Creative Therapy Patient Survey

Wendy Taylor, Clinical Compliance & Governance Lead at LOROS shares findings from a recent survey of LOROS patients' experiences of engaging with Creative Therapies...



Wendy Taylor (inset) and LOROS Day Therapy Patients (right) during some of the creative therapy sessions

Creative
Therapy offers
up an
opportunity to
express
feelings which
are too
intense or
painful to put

into words in a safe environment.

This creative process has been shown to reduce depression, stress, anxiety and promote relaxation, it can also help with pain relief. It may promote a greater understanding of who we are, our feelings and emotions.

Participants are encouraged to express themselves using different materials. No special skills or previous experience are needed. Nothing is considered wrong in Creative Therapy, no one judges the finished creation. New possibilities can be gained from the therapies and many find it is a rewarding and meaningful experience.

The aim of the survey was to explore the patient's experience of engaging with Creative Therapies, the benefits of the Therapy to the patient, the quality of the relationship with the Therapist and patient priorities for future service delivery and development.



A simple self-completion survey was developed by the Clinical Compliance/Governance Lead in partnership with the Creative Therapist and Day Therapy Manager at LOROS. 16 surveys were distributed during January and February 2016 to patients who take part in Creative Therapies as part of the LOROS Day Therapy programme.

16 surveys were returned (100%)
Patient responses are shown below....

What do you like about the therapy you take part in?

- It gives me a chance to try things without any pressure. It is very relaxing. It is also easier to chat and talk things through with others who are doing something creative
- It keeps my mind active
- Giving and getting support from the other participants
- I have achieved things I never thought I would be able to do
- I am not good at relaxing but find this art activity does this
- I enjoy being free to expand my creative ability
- It's a morale booster
- It is interesting, productive, keeps my mind alive and helps my speech
- It is better than falling asleep in a chair

If you were able to have more creative therapy, what would you like to get out of it?

- Be able to achieve more to share with my family the things I have made
 to create memories
- Flower arranging
- Painting
- Craft work
- I would appreciate the same sessions more often, two weekly seems a long period
- More of what I am already receiving
- To try new things
- Photography

How sensitive has the Therapist been?

Very sensitive – 94%

Quite sensitive – 6%

Not very sensitive – 0%

What has been the benefit of the Therapy for you?

It boosts my self- esteem – 88%
It relieves some of my stress – 100%
It distracts me from physical pain – 69%
It distracts me from difficult and painful emotions

It has a positive effect on my quality of life – 81%

Patients were invited to make open ended supplementary comments...

- I much appreciate the efforts made by the team, the staff are excellent
- Thank you for all your help
- I really appreciate everything, the Therapies are a godsend
- I come in feeling very low, tired, in pain and I go home feeling light, happy and in less pain

Improving Healthcare Through Clinical Research

How are treatments and cures discovered?

What is the impact of clinical research?

■ How do we undertake clinical research?

Why do we do clinical research?

If you would like to learn the answers to these questions, and learn more about clinical research, the National Institute for Health Research (NIHR) Clinical Research Network (CRN), in association with the University of Leeds, is giving you the opportunity to join a **FREE** online course, starting June 6th.

The MOOC (Massive Open Online Course) is **open to EVERYONE**. The online content offers a flexible approach to learning, and online course moderators will offer guidance along the way, with interaction from other learners, and interactive materials available throughout the course.

It will take four weeks to complete (at around 4 hours per week), and is worth 16 CPD points (certificates will be available upon completion of the course).

To find out more, click here.

LOROS Research Bursaries Return for 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 Manger 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. The project must intend to improve LOROS services and benefit patients and families that we care for.



Good Clinical Practice & Research Consent Training

Dates below, facilitated by the University
Hospitals of Leicester, to be held in the
Professorial Seminar room, LGH. For information,
or to book, email:

RITraining@uhl-tr.nhs.uk

Wed 08 th Jun	GCP 1	09:30-12:00
Wed 08 th Jun	GCP 2	09:00-12:00
Wed 08 th Jun	Consent	12:30-14:45

*GCP 1 is for Non-CTIMP studies
GCP 2 covers both Non-CTIMP and CTIMP studies

Leicestershire, Northamptonshire & Rutland (LNR) Audit & Research Day

21st June 2016, 1:30 - 5:00pm

LOROS Hospice

This event is open to professionals across Leicestershire, Northamptonshire & Rutland. The programme includes presentations of local research and clinical audit projects.

> For more information, please contact: <u>christinafaull@loros.co.uk</u>



PROMOTION OF
EXCELLENCE IN
PALLIATIVE CARE



The LOROS-DMU Centre for the Promotion of Excellence in Palliative Care (CPEP)

Annual Lecture 2016

The thing about life is...

Laura Middleton-Green, Marie Curie Clinical

Academic Research Fellow in End-of-Life Care,

University of Bradford

6:00pm, Wednesday 9th November, (Reception & Buffet from 5:30pm) Frizelle Suites, LOROS Hospice, Groby Road, Leicester LE3 9QE Cost: FREE

To reserve a place, contact the LOROS Education Team on: 0116 231 8455

Email: education@loros.co.uk