

Research NEWS September 2014

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

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Issue N^o 6

An Update from the Research Team...

& Important Information About Bursary Funding for LOROS Staff



Paige Murney is a welcome addition to the Research Team.

As Summer is drawing to a close, we can reflect on what a busy few months it has been for the research team.

Firstly, a new face has now joined us... Paige Murney has recently completed

an NVQ Level 2 in Business Administration, and has joined the research team, one day a week, alongside working for the Education team, supporting research administration.

Paige successfully beat 600 entrants in the biggest amateur boxing tournament in the world - the Harringly Cup - back in June, so the research team won't be arguing with her!

Idaliza has now also successfully completed an Open University module looking at *Investigative & Mathematical Skills in Science*, and hopes to use her learning to develop her role within the research team.

In addition, Christina Faull has had an oral abstract accepted for the 25th International ALS/MND Symposium, which will be taking place in Brussels in December - so look out for feedback from the conference in the next edition of the newsletter!

Zoebia Islam has established a new Research Reference Group; a task group with the aim of promoting research within the Hospice. If you would like to become involved with this, please speak with Zoebia or email her: zoebiaislam@loros.co.uk



We are excited to announce that, if you are a member of LOROS staff who would like to become involved in research to improve LOROS services for the benefit of patients and families that we care for, you can apply for a research bursary.

It may be that you want to attend, or present at, a conference; go on a research training course; secure funding to backfill your time so that you can develop an idea or a project; or are looking for support with fees to support a research qualification. If you would like further information, please speak with a member of the research team, or email: research@loros.co.uk

The closing date for applications is October 15th and ALL staff are eligible to apply.

Transfer of LOROS's Knowledge about Lymphoedema to Transform Care LOROS Welcomes Rebecca Gaskin...

LOROS is poised to take a leading role in a two-year 'Knowledge Transfer Partnership' working with Nottingham University and 3M Health Care Ltd in Loughborough. The project will be facilitated by Rebecca Gaskin. It involves building consensus between GPs, community services and LOROS around the optimal care pathway for patients with chronic oedema, many of whom will not have cancer causing their oedema. Once agreed LOROS and the community nursing teams will trial the

recommendations for the new care pathway. The objective is to provide robust evidence of the pathway's usefulness and whether it saves money and improves care for patients.

Rebecca, a 'Brummy', graduated from the Open University in 2012 and is working towards a Masters by Research as part of this project. She has already started getting to know the lymphoedema and research teams and will regularly be seen around LOROS over the next two years.



Rebecca Gaskin will be a welcome face at LOROS over the next two years.

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LOROS

Hospice Care for Leicester, Leicestershire & Rutland

Being there for you
and your family



Originally from the Medway Towns in Kent, David Barnard has lived in Leicester since 1973, with his wife, whom he met whilst working overseas in India. They have two sons.

David worked as a Senior Manager within the field of Social Work, for a number of years. His connection with LOROS began after one of his son's was diagnosed with a brain tumour in 2007; a time he describes as the moment when "our lives changed, forever".

Since then, he has shared his experiences as a carer; becoming involved with the LOROS Patient & Carer Participation Group, and the Five Senses Survey, which trains volunteers to discreetly observe clinical and non-clinical areas of the Hospice, using their five senses to identify what is working well and what could be improved.

David became involved with research at LOROS after he was approached about the VERDIS study, which looks at how video-recordings of clinical consultations can be used for the purpose of research and for the teaching of communication skills to healthcare professionals. He now attends key meetings about the project, advising and informing developments in his capacity as lay representative.

How did you come to be involved in research?

I've been interested in research for some years, but in different fields to the medical profession, until, really, for my son's sake I had to start looking. Often my son was too tired or too ill to take anything in, or to do anything, so you develop a joint way of working within a family

There is of course research, and 'research' – it's like saying there are statistics and damn lies basically. There are also screaming media and internet headlines on miracle cures, especially for cancer. Being human, and in pain/anguish/need, we grasp at straws – we become vulnerable.

All those things I've become aware of, which makes our family more aware of the constraints on the professional people, so in effect you begin to share not only knowledge but understanding of each other.

Why do you think it is important for LOROS to be involved in clinical research?

I feel that research is important to LOROS.

LOROS is very different to the NHS; smaller, calmer, quieter. It can offer unique insights, not only into the medical care but also into patient/carers/professional interaction and, in particular I feel, in to providing understanding, care and development, in treating the whole person rather than just the apparent illness.

Do you feel that the perspective of lay representatives/patients can bring an important viewpoint to research meetings, such as stakeholder or focus groups?

I think it's probably one of the most important developments happening at the moment. I felt for a long time as a Social Worker and quite senior Social Work Manager that clients and families should be more actively involved in decision making. Now, after our direct experiences of medical services, I feel even more strongly on this subject. I feel that whether this happens or not depends on whether the professional agencies and the individual staff have the self-confidence in their abilities and empathies with patients/carers to face up to possible challenges or suggestions they may not really like.

How do agencies and their staff understand the effect of their services – their attitudes, their collective conventional wisdom – on the people they are supposed to be assisting, if they don't allow those people to tell them. After all, many patients/carers have been professional people themselves, or qualified, and experienced in many other walks of life, used to discussions and making decisions in very difficult areas.

If you can build up people to be involved in every sphere of the services...who else can give LOROS the information that they need. And it need not be at high level – think of all the small, well thought out, lower key levels of research you can do – as with the 5 senses – where you can smooth out administrative problems that people are facing because you know about them...It's not only in the medical sense, it's also in the sense of a well-run organisation.

In what ways do you feel that research can make a difference to patients and carers?

It's a two-way street basically, because my involvement at a low key level in research – and more I think in participation – has helped me to learn a great deal which I can pass on to my wife and son and to other people, without being a specialist in those kind of things or trying to dress myself up as a specialist.

It widens knowledge and understanding but it also makes you much more aware of what the professional person faces every working day of their lives. The constraints, the stress, the tension, the problems....You begin to understand more about what's happening.

In effect, you begin to share not only knowledge but understanding of each other.

Do you think there are any assumptions about research that deter people from becoming involved?

Yes. I feel the reluctance is due more to patients and carers feeling they have little or nothing to offer, or unsure about attending meetings etc., and with professional staff. That's really why I'm so glad that LOROS is making such an effort in helping patients and carers to participate in every sphere of research;

because I think if people can start to participate at one level, then they can move on because they gain confidence, and they realise they do have something to offer. I really do feel it is important for the development of any agency really, not just LOROS, to listen to those people.

People may also be wary or frightened of exposing the kind of pain and anguish that they've been through.

And that means that LOROS has to develop the skills to draw those people in.

What do you think LOROS should do in order to help that?

It's important that LOROS uses every opportunity – whether that's posters, pamphlets, whatever – and it does to a great extent – to involve, and to draw people in; and, in my experience of the Patient and Carer Participation Group, that is happening.

What value do you think there is in research having more of a presence - a 'face' - at LOROS; i.e. through patient leaflets/posters?

I think it's one of the emerging areas that hospices and other voluntary agencies, like LOROS, have to work on.

It's very important. I think it needs to develop so that it draws people in gently. I would see research as possibly the further end of a progression of involvement by patients/carers. I don't think it's something you can suddenly grab hold of somebody and say "would you like to be involved in this research", unless they've already made some kind of commitment to LOROS, in

whichever way they're doing it.

It's preparation – getting people to understand the benefits for others and for the medical professional staff.

If it can't be done in an agency like LOROS, then it won't be done in the vast agencies out there.

What would your advice be to other patients/carers who are interested in becoming involved in research?

What I would suggest is pretty simple really...firstly, accept that you *do* have something to offer by being a patient or a carer. You have direct experience of being on the receiving end, and what you receive is sometimes not what you want or what you need.

Also, do not try to become a professional yourself...remain what you are; someone who wants provisions for people to improve and develop. What I've said is that you have the experience which the professional staff, in the main, don't have, which is being on the receiving end. The professional staff give and you have to take, but what seems to have been forgotten over the years is that the people who take can also give back.

Things work better if the provider and the receiver actually work together to understand and then you find out that you have something to give as well.

I also feel that it's important to understand the need for confidentiality on the part of the patient/carers representative when becoming involved in this way.

Jeanne Rae became involved with LOROS in 2005, when her husband was referred for pain management, after what had been "a difficult journey" for both of them. Jeanne describes her husband as someone who "loved life"; throughout his illness, he worked determinedly to raise funds and, more importantly for him, awareness. He threw himself into a number of challenges – cycling the length and breadth of Scotland, taking on Cape-to-Cape events in both Scotland and Ireland, and establishing the first in a series of annual jazz events – funds from which go towards LOROS and PROSTaid, a charity he was instrumental in establishing. Since her husband's death in August 2007, Jeanne has continued to raise funds and awareness, and has also become involved as a lay representative; initially for the Patient & Carer Participation Group, and more recently, as a member of the VERDIS study Advisory Group.

How did your links with LOROS develop, after your husband died?

I had always wanted to give something back to LOROS but it took around four years after my husband died before I finally felt able to become more involved. I responded to an appeal for help in a copy of the [LOROS] magazine but I wasn't sure what I could offer.

In the magazine they talked about patient/carers committees, so I volunteered to be a representative on the Patient and Carer Participation Group as I am particularly interested in the dialogue between patients and carers and I'd had such a brilliant experience with the communication here [at LOROS].

Whilst at a patient/carers meeting I happened to see the doctor

who cared for my husband. I told him this was an area I was interested in and a short while later I was contacted by LOROS about the VERDIS study. I thought it sounded very interesting and said I would very much like to be involved. I subsequently spoke in more depth to Ruth Parry, who is leading the research.

Good communication is about being very sensitive to the other person's needs. Sometimes your desire to say something can be greater than that persons need to hear it; it's a finely judged balance.

For example, one of the doctors who cared for my husband told me that she was able to recognise when I'd had as much



as I could take when I started to respond to her questions in a particular way. At that point she used to say, "I'll stop talking to you now because I can see you can't take any more". That experience has stayed with me. I thought it was extremely caring, very intuitive and so helpful.

The staff [at LOROS] deal with people at their most exposed; people who may normally be very controlled. LOROS provided an incredibly safe space for me to be able to talk frankly about my concerns without feeling as if I was being disloyal to the patient.

Do you feel that the perspective of lay representatives/patients can bring an important viewpoint to research meetings, such as stakeholder or focus groups?

Very much so. Care is about people. With research or stakeholder meetings there are protocols, systems and processes that have to be followed but it's important to remind yourself that this is about people.

Research is like a hot air balloon in the sky; all the protocols and processes are the fire and the balloon, but underneath there's a basket with people in. Like the balloon, the processes and procedures need to be strong, but without the people you've just got a balloon floating free.

Do you feel it's important that LOROS continues to go down the road of research and looks at what research findings can do to help benefit the patient experience?

Absolutely, because for all I've had brilliant experiences here, I've had some dreadful experience of patient communication in the NHS. Not because staff are cruel, but because they're busy and it's not their focus.

I think hospices, in the main, get it right. Research can help ensure that they carry on getting it right, and some of the results may cascade out to other professionals, which I think it's brilliant. That's why I wanted to be involved.



Julie Gardner's connection with LOROS began shortly after her husband was diagnosed with Motor Neurone Disease, in September 2007. Julie, a retired teacher who now works as a Special Needs Coordinator, took to writing poetry after her husband's death, and also writes for a local magazine. Her involvement in research began when she was approached to give an interview about her experiences for Professor Christina Faull's study, looking at the Withdrawal of Non-Invasive Ventilation in Patients with MND.

Do you feel that the perspective of lay representatives/patients can bring an important viewpoint to research meetings, such as stakeholder or focus groups?

I definitely do. I think it's difficult for professionals sometimes because in the medical field, or in the educational field that I work in, there's understandings we take for granted, but I think talking to people who are lay people, if you really listen, and really work out what they're trying to say, often not having the vocabulary to say it because they've not got that jargon, I think that's where early insights can happen.

Do you think there are misconceptions about research?

That it's clever, highfaluting stuff – it's not for me!

Have you found that you are more aware of research generally now, as a result of your involvement (i.e. what is happening in the newspapers /TV with a research focus)?

Because my husband had prostate cancer and was involved in trialling drugs [within the NHS], I was aware of some of the processes through which drugs are researched.

VERDIS has definitely given me an insight into how rigorous the whole research process is.

What would your advice be to other patients/carers who are interested in becoming involved in research?

One of the things that held me back a little was the length of time that had passed before I volunteered. I wondered what value I could add after such a gap?

I've realised that just because you can't do something immediately, your experience is still valuable and can be made use of. If you feel you want to do something, just get in touch with LOROS.

How would you encourage professionals to ask if patients/carers would like to become involved in research?

The VERDIS research looked in great detail at how and when people are contacted with regard to studies. In my case the article in the magazine acted as a good prompt but I know from patient groups that it's a real challenge for professionals to know when it's a good time to encourage people to get involved.

Hospice care is one of those things that you don't think about until you need it, and then when you need it, you're busy dealing with illness. Some people may wish to be involved in the immediate aftermath of bereavement whilst others, like me, need more time.

There's no one answer. I think the only thing you can do is keep channels open, and remind people that there are many ways they can support LOROS, including research.

From your experience of being interviewed for a study, do you think that is the case?

I don't think that's the case.

I think of research as being something that's academic, but it doesn't have to be, does it. Research can be, in simple terms, we want to know what you think or what your experience is. A lot of people, I suspect, if you said to them "Would you be interested in taking part in research?" might be put off by that; but if you said to them "We really want to know what you think and what your experiences have been, because that will help us in the future" that would be a very different way of putting it.

Do you think it's important that LOROS continues to support research, moving forward; that it continues the forming of new studies and collaboration with other professionals, universities and healthcare settings?

Yes. I think it's very important. Not least because I think death is still a taboo subject. What LOROS is about – end of life care – needs to be talked about, discussed and brought to the table.

What would your advice be to other patients/carers who are interested in becoming involved in research?

I would encourage them, and I would say perhaps contact LOROS. I think it's helpful to share experiences and I think if people tell their stories, it adds to the understanding of what matters. The more stories that you hear, the more you start to make sense of what's going to be offered and how it can be offered in different ways.

The Research Team would like to take this opportunity to thank the three carers who agreed to be interviewed for the purpose of this newsletter – David, Jeanne and Julie.

The sharing of experiences such as theirs is a valuable way of highlighting the benefits of research, but also allows us to learn more about how processes and procedures can be improved upon for future patients and carers.

You Said... We Did!

In our May newsletter, we advised you that findings from the October 2013 LOROS staff Research Questionnaire were being turned into recommendations to help shape the development of research at LOROS. We have now started to put those recommendations into action, and thought you would like to hear an update on our progress so far...

I would like to see more information made available about new evidence to inform care, and improved access to journals/findings.

You can find out more in our 'Welcome to LOROS Library' article in this newsletter.

I would like to see more study days with a research focus.

Zoebia Islam ran 'Beginners Guide to Research' study day in July...feedback from the day was positive and we plan to run it again next year. In addition, the Evidence Based Practice research course, also led by Zoebia, commences for the second time in October 2014 (for more details see *Dates for the Diary*).

I would like to see service users have a better awareness of research at LOROS.

Soon to be on display.

I would like to work with the research team, to see how research activity could become stronger at LOROS.

The new Research Reference Group met in August and September, led by Zoebia. Get in touch if you want to join in!

I would like to see Research become a regular item at monthly Heads of Department meetings (HODs), to encourage 'manager' involvement.

Mandy Motley, Director of Education & Training, now cascades research news, on behalf of the research team.

Perhaps you have an article that you would like to share with our readers?

If research has had a direct impact on you as an healthcare professional, and impacted on your practice, then we would be interested in hearing about your experience.

If so, please get in touch with the team: research@loros.co.uk



Welcome to the LOROS Library...

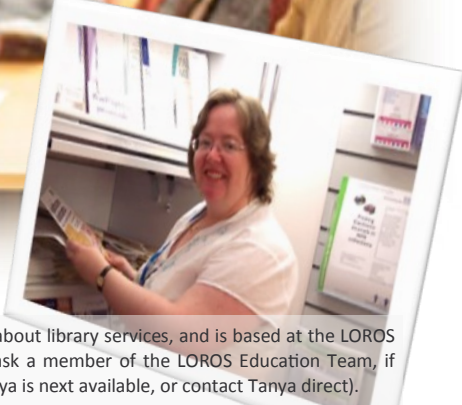

By Tanya McLaven, Deputy Librarian, UHL

LOROS Library is for all LOROS staff and students on placement at LOROS. The library guide is available at: <http://www.uhl-library.nhs.uk/pdfs/loros.pdf>

You can join and obtain a LOROS library card by completing a membership form via the Education Department office, LOROS or completing an online registration form at: <http://www.uhl-library.nhs.uk/regform.html>

You can borrow up to six items and you can search the library catalogue at: <http://uhl.nhslibraries.com/>
By completing an advanced search you can search for books just at LOROS library.

As well as books, LOROS library has a number of journals, and articles can be photocopied. You can search online for journal articles on any topic using a number of health related databases such as Medline, Cinahl and British Nursing Index via: <http://www.library.nhs.uk/hdas/simple>



Tanya McLaven can offer advice about library services, and is based at the LOROS library once a fortnight (please ask a member of the LOROS Education Team, if you would like to know when Tanya is next available, or contact Tanya direct).

Please contact Tanya McLaven on: 0116 250 2303
Or email: Tanya.McLaven@uhl-tr.nhs.uk
to find out more about any of the above services

An NHS Athens account is required to search for journals. You can self register at: <https://openathens.nice.org.uk/> or contact Tanya McLaven, Deputy Librarian: Tanya.McLaven@uhl-tr.nhs.uk or 0116 250 2303, who can register you for an Athens account.

Tanya is available at LOROS library once a fortnight to provide support to staff and students. Tanya can provide training on database searching skills and critical appraisal. A literature searching service is provided for you if you want information to support clinical practice. Other services provided include current awareness (table of contents alerts) and interlibrary loans for journal articles and books.

The LOROS library is equipped with 4 computers, for any member of staff to access at any time of the day (this includes evening and night staff).

There is no need to book a computer and staff can login using their LOROS username and password.

If you require assistance with the use of a library computer, please contact Rachel Lovett in the Education office.



A useful website: <http://www.evidence.nhs.uk/topic/palliative-care>

...links to national NICE palliative care guidelines
and general information relating to palliative care



Caring to the End:

Young People with a Parent in the Last Year of Life

LOROS Welcomes Nicola Turner...



Nicola Turner will be a regular face at LOROS over the coming months.

Nicola Turner, is a PhD Research Student at the Sue Ryder Care Centre, University of Nottingham, and has joined LOROS as an associate researcher until May next year.

Nicola is undertaking a study to explore young people's experiences of living with a parent who is in the last year of life.

Staff at the Hospice are supporting the study by helping to identify young people and families who may be willing to take part and share their experiences.

the way families manage changes in everyday life when someone is ill has far reaching consequences for young people, and for the choices they make about education, employment and relationships. If we can understand more about young people's experiences during this time, we can begin to develop better ways of identifying those who may need extra support.

If you see Nicola at LOROS, please stop to say 'hello'. Or, if you would like to find out more about the study, Nicola can be contacted by email at: nxtnt4@nottingham.ac.uk

Little is known about young people's involvement in family care when a family member has a life-limiting illness. We do know that



Evidence Based Practice 2nd October 2014 for 11 weeks

This module is suitable for staff and students working across health and social care or for anyone with an interest in research.

It can be taken as a standalone module for continuing personal development, or as part of the LOROS accredited Foundation degree programme. Or, you can attend individual sessions.

Cost: £310 accredited

or £150 for CPD (continuing personal development)

Topics will 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.

For more information contact LOROS Education:
0116 231 8455 or email education@loros.co.uk

A Cup O' Learning & A Slice O' Cake:

Acceptability of Early Intervention services in mental health for BAME communities: Some Lessons learned

**22nd October 2014
(12:00 - 1:00pm)**

Frizelle 1 LOROS Hospice (free to attend)

Zoebia Islam will discuss the 'ENRICH' study findings, looking at the acceptability of early intervention in mental health in BAME communities. What can be learnt about explanatory models of illness that may be applicable to palliative care?

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

CPEP ANNUAL LECTURE 2014
Hospices and universities working together:
Does it raise the game? Reflections from
the Cicely Saunders Institute

FREE EVENT
Wednesday 12 November, 6pm reception,
6.30pm lecture followed by refreshments
Hugh Aston Building, De Montfort University

Professor Irene J. Higginson OBE,
Director of the Cicely Saunders
Institute, King's College London

Professor Higginson is Director
of the world's first purpose-built
Institute of Palliative Care and
is at the forefront of research
in palliative care nationally and
internationally. She has published
over 400 articles in peer reviewed
journals, as well as several books.
In this lecture she will reflect
upon partnerships between
universities and hospices and
how these can enhance research,
learning and care.

To book please visit our website dmu.ac.uk/events,
email eventsoffice@dmu.ac.uk or call (0116) 250 6031

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

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

Annual Lecture

12th November 2014, 18:30 - 19:30 (reception from 18:00)
Hugh Aston, De Montfort University

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

For further information, please visit the DMU website:

<http://www.dmu.ac.uk/about-dmu/events/events-calendar/2014/november/hospices-and-universities-working-together-does-it-raise-the-game-reflections-from-the-cicely-saunders-institute.aspx>

To book, contact the DMU events office on:
Events Office on (0116) 250 6031 or email
eventsoffice@dmu.ac.uk