



LOROS Hospice Centre for Excellence

In collaboration with the University of Leicester

RESEARCH REPORT April 2022 – March 2023

Report prepared by:

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Summary of our work April 2022 – March 2023



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1. The Research Team

LOROS based team

Professor Christina Faull, Research Lead and Consultant in Palliative Medicine. Honorary Professor Department of Population Health Sciences, University of Leicester.

Dr Zoebia Islam, Deputy Research Lead LOROS Hospice and Associate Professor in Palliative Care and Frailty, Department of Population Health Sciences, University of Leicester.

Tara Maitland, Research Manager & Honorary Fellow, University of Leicester.

Dr Lucy Bleazard, Clinical Research Fellow.

Sue Ashton, Research Nurse.

Shona Agarwal, Research Associate.

Sarah Worthy, Senior Research Administrator and Personal Assistant to Christina Faull.

Siddiqa Reininghaus, Research Assistant and Administrator.

Janis Hayward, Research Volunteer.

University based team

Dr Fawn Harrad-Hyde, LOROS Research Associate in Palliative Care and Frailty, Department of Population Health Sciences, University of Leicester.

Dr Linda Birt, Associate Professor in Palliative Care and Frailty, School of Healthcare, University of Leicester.

Dr Chris Williams, LOROS Clinical Lecturer in Community Palliative Care and Frailty Department of Population Health Sciences, University of Leicester.

Kay Phelps, Research Fellow, University of Leicester.

Emma Regen, Research Fellow, University of Leicester.

Chandini Subramanyam, PhD Student, University of Leicester.

Honorary team members

Dr David Wenzel, Academic Clinical Fellow (to August 2022).

2. Working in collaboration with patients, family and the public (PPI) and other stakeholders

We have worked with 91 people to help shape and undertake our research and to support dissemination of the findings. Six people continued their involvement in the Thinking Ahead project. Ten people have been members of the LOROS research consultee group and more than 60 people have worked with us to shape research questions and grant applications for future work to improve care of people from minority ethnic communities and family who are caring for a loved one who is dying.

At the University of Leicester ten regular consultees have supported the LLR Older Person's Research forum, facilitated by our group and five members have been involved of our study into the lived experience of frailty with respect to ethnicity. Our group is increasingly seen as a leader in PPI and co-design within the University.

Each of the research projects we lead has a bespoke PPI group and where possible, a PPI coapplicant/lead role.

Carers Matters

We have drawn together and established an extensive group of family carers, voluntary, social care and health care stakeholders with the shared aim of improving the wellbeing and empowerment of family carers of people who are at risk of deterioration and dying. The group has shaped our research, supported recruitment, heard about and commented on findings and collaborated in our project to provide more education and empowerment to help family carers. A small grant from the Academic Health Sciences network helped develop this group.

Community Connectors

The LOROS 'Thinking Ahead' study (HS&DR 17/05/30) found that people from ethnically diverse communities have limited knowledge of end of life care and end of life care planning. We identified that communities need to hear information from people that they trust and see that researchers are working in partnership with them. We developed a project proposal to address these gaps (LIISTEN Bid) through the development of sustainable research partnerships between ED communities, care providers, practitioners, academics, and voluntary sector groups across Leicester City and Leicestershire.

As part of our pre-project development work for a grant application to address these gaps (LIISTEN: Learning from within innovative inclusive sustainable research partnerships with ethnically diverse groups to address equity in end-of-life care) we received funding from NIHR RDS Public Involvement Funding and held discussions with nine voluntary and community groups about the purpose and scope of this project and their potential role as partners or collaborators. As part of this we also held consultations with 50 men and women

from ethnically diverse communities (including Bangladeshi, Pakistani, Turkish, Black African Caribbean and Black Caribbean). These discussions were led by the project lead (Zoebia Islam) and convened and facilitated by our invested partners Healthwatch Leicester and Healthwatch Leicestershire and Bangladeshi Youth and Cultural Shomiti. Consultations were tailored to meet the diverse language and communication needs and levels of education, and understanding of the specific community group members. The diversity in these factors impacted on the discussions held and time taken. Language used had to be simplified particularly when explaining end of life care and end of life care planning, resuscitation and palliative services. There are no direct translations for these words and concepts in the first languages of many of the consultees. These discussions have emphasised the need for this study highlighting lack of knowledge and inaccessible and inappropriate information sharing about the choices available to people with advanced illness who are at risk of deterioration and dying.

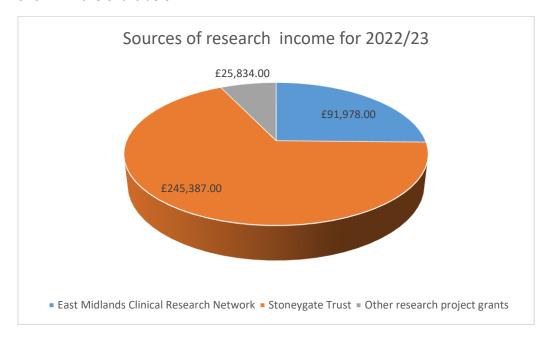
Older people's PPI group at University of Leicester

The Leicester, Leicestershire and Rutland Ageing PPI Research Forum has continued its work supporting the development of research ideas and ensuring that research is patient centred and relevant to the needs of older people. This year the Forum has worked with academic teams both internal and external to the University of Leicester on a range of studies including: healthy cognitive ageing; tackling anti-biotic over-use in primary care and understanding experiences of frailty with respect to ethnicity.

Kay Phelps and Emma Regen secured a small grant from the University to engage underrepresented communities in the work of the Forum and the College of Life Sciences more broadly. Two workshops were held with White British working class and South Asian communities respectively. These explored people's priorities for health care research, barriers to engagement in PPI activities and support and training needs. The majority of participants agreed to be contacted about future opportunities for involvement in research and PPI activities.

3. Finance

LOROS received a total £364K income for research during the year. The derivation of this is shown in the chart below.



Additionally, Chris Williams secured £7,000 for the University of Leicester Economic and Social Research Council (ESRC) funding for Understanding the varied experiences of frailty in older age with respect to ethnicity.

We also secured funding for clinical staff aspects service delivery of our Pre-transfer clinical decision assessment (PTCDA) pilot of £480,000. From the Leicester, Leicestershire and Rutland CCG (now the Integrated Care Board). This finding is managed by Charnwood GP Network

4. Recruitment to Research Studies

We screened 340 potential participants and recruited 74 people to 10 research studies in the year.

Study Title	Study Description	Sponsor	Start Date at LOROS	Scheduled End Date at LOROS	In year Recruitment
MND National Register The Motor Neuron Disease Register for England, Wales and Northern Ireland.	This study involves recruiting patients with MND and requesting their consent to have their medical details entered onto and stored in a national database. Data is collected via a secure web-based data collection tool.	Kings College London	Jan 2019	Nov 2025	21
COMMEND A feasibility study & randomised controlled trial of Acceptance and Commitment Therapy for people with motor neuron disease.	This is phase 2 of this study which entails 15 sites recruiting 188 people collectively over 20 months (12-13 patients per site). This study involves the trial of a therapy called Acceptance and Commitment (ACT) therapy to patients with MND. It will involve interviews / delivery of the therapy and is a randomised controlled study. LOROS have 3 therapists who are trained in the delivery of the ACT therapy.	University College London	July 2019	July 2022	2
VENT MND – Exploring Decision Making with Patients with MND Using Home Ventilation.	A study to explore patients' and family members' experiences of end of life decisions about continuing or withdrawing mechanical ventilation in Motor Neurone Disease (MND). The study comprises qualitative interviews with bereaved family members and with patients who are dependent on home mechanical ventilation	University of Nottingha m	May 2021	Dec 2023	1

OPTICALS - (HighCALS - A randomized controlled trial of the HighCALS intervention versus standard care in	To develop and test a complex intervention (HighCALS) to enhance the nutritional management of people living with ALS, leading to improvements in survival and quality of life. The study aims to see if calorie and dietary intake improved patient outcomes.	University of Sheffield	24/02/202 2 Re opened Jan 2023	April 2024	1
ALS). ACCESSA: Access to healthcare by ethnic minorities, with a focus on South Asian communities.	The ACCESSA study is a project using narrative to explore participants' own stories about healthcare in South Asian communities. It aims to examine the ways in which patients and/or their family members have experienced their journey to using healthcare services through qualitative interviews. The study aims to identify ways to improve access to care in the South Asian community.	University of Leeds	28/03/202	31/08/2022	2
CHELSEA II: Alternative forms of hydration in patients with cancer in the last days of life.	The study is a cluster randomised trial with primary outcome in relation to delirium. Research sites are randomised to give either standard intervention A: continuance of oral intake and regular mouth care, or standard intervention B: continuance of oral intake, regular mouth care and clinically assisted hydration. LOROS was randomized to B.	Royal Surrey County Hospital NHS Foundation Trust	Jan 2023	Nov 2023.	3
An online peer-to-peer support programme for carers of individuals with motor neurone disease requiring ventilatory assistance	Randomised Control Trial of online peer support programme based on system developed in Canada.	Kings College London	April 2022	Aug 2024	4
MiNDToolkit: Practical Management of Cognitive and Behavioural Impairment in Motor Neurone Disease	The randomized controlled study aims to test the feasibility of the new MiND toolkit for caregivers. The toolkit provides clinical reasoning tools for HCPs and educational tool and techniques for caregivers of those people with MND who may have behavioural or thinking problems.	University of East Anglia (UEA)	April 2022	Dec 2022	3

We are also close to completing 4 additional studies that are not actively recruiting during this term.

5. Studies in preparation for 2023-24

Study Title	Study Description	Sponsor	LOROS' Role	Due Start Date (approx.)
Anxiety Management and	This is a mixed methods study. Qualitative data will consist of participant	University of	Lead site	June 2023
Breathlessness: A pilot study of	diaries and semi-structured interviews. We will also use participant diaries to	Leicester		
Alpha-Stim AID Cranial	assess compliance and adverse effects, looking at how frequently the Alpha-			
Electrotherapy Stimulation (CES)	Stim AID device was used for and how long for, and if any adverse effects			
as a treatment for anxiety in patients who experience	have been recorded. A number of standardized questionnaires are used to			
breathlessness due to advanced	measure anxiety, breathlessness, sleep, mood and quality of life.			
chronic respiratory disease.	The device used in this study is CE marked and used within its licence.			
CRISIS - Understanding COVID-19	This is a qualitative exploratory study that will take place in Leicester City and	University of	Lead Site	May 2023
experiences of Black Asian and	Leicestershire, UK. Interviews will be undertaken with patients from ethnically	Leicester		
Minority Ethnic patients'	diverse backgrounds with End Stage Kidney Disease on haemodialysis			
discussions with Health	treatment, bereaved family care givers, and health care professionals who			
Professionals about Deterioration	support them recruited from the General Hospital renal unit, Hamilton renal			
and End of Life.	unit and Loughborough renal unit (PIC sites).			
TV Life: Understanding living with	This study will explore patient, family and health and care professional	University of	PIC Site	May 2023
tracheostomy ventilation for	experiences of using tracheostomy ventilation	Nottingham		
Motor Neurone Disease (MND)	(TV) to support breathing for people with Motor Neurone Disease (MND).			
PCARE: Principles for research on	The study aim is to produce guidance for researchers on how methods can be	Hull York	Recruiting	May 2023
ethnicity in palliative and end-of-	improved to understand the relationship between ethnicity and palliative care	Medical	(ZI Co-app)	
life care: development of a	in the UK.	School		
consensus statement.				
Equitable Bereavement Care for	This study aims to understand why ethnic minority communities have, or have	Kings College	PIC/Recruit	September
All – An inclusive, qualitative	not, made use of bereavement services. Through in-depth interviews, this	London	ing and	2023
study to improve bereavement	study will understand how current bereavement services provide care to		training (ZI	
services for those from ethnic	ethnically diverse community members. These findings aim to improve what		Co-app)	
minority groups.	bereavement services can do to improve, and better meet the needs of ethnically diverse community members.			

6. Thinking ahead about medical treatments in advanced illness

A qualitative study of barriers and enablers in end-of-life care planning with patients and families from ethnically diverse backgrounds.

We submitted the final report for this four-year NIHR funded (454k) project in December 2021. It is challenging to summarise the wealth and richness of the data succinctly but the headline findings are:

- ➤ Building **rapport** and **engendering trust** between HCPs and patients/families should be a key endeavour and it is strongly dependent upon:
- Effective and timely communication at both interpersonal and systemic levels; in a way that maximises the opportunity to optimise care for 'that' person at 'that' point in their life journey
- Knowledge of the 'whole' person and what influences may be impacting their experience of illness and care and the decision-making and planning that it may require
- Empathic engagement with varying care needs that may arise as a result of diverse cultural and religious priorities
- Developing skills in communication is key to enable authentic cultural curiosity, (understanding of what is important to the patient and family in their life and in the care as they deteriorate) and opportunities for open and honest discussion about prognosis and end of life
- Removal of barriers to communication and understanding posed by language and accessibility of information
- Additional practical complexities exist for ethnic minority groups, including those associated with obtaining death certificates; assembling family in a timely way; possibility of large numbers wishing to visit; misunderstandings due to language (in diagnosis and prognosis situations).
- As well as enabling autonomy and agency for patients and their families in their decision-making, they may welcome **professional input to decisions**; HCPs can ease difficulty in key decisions by providing expert knowledge and explanations, time to talk, space to reflect, additional information as well as reassurance and direct advice and guidance. Professionals should seek to understand the dilemmas for the patient and their family through authentic curiosity and signpost to potential resources.
- There is often a lack of awareness of specific culturally- and religiously-driven desires or needs, and a perceived lack of such representation in care services. Choice of direct care may be influenced by religion and/or culture; there is perceived poorly-matched availability of care where specific diverse needs may not be met and culturally competent care is often desired but sometimes lacking

Specific **religious and cultural influences impacting care** include:

- Varying awareness and openness to available care options
- Cultural and religious influences on model of care such as cultural norms or home/family-centric care; where external care cannot be sought
- Religious or community affiliation may help with care/support broadening care network
- Generational or personal difference re religious and/or cultural observances some talk about adhering, not adhering quite so much to religiosity or cultural norms etc.
- Religious reward or fear of stigma influencing care, as well as diverse connotations (religious and/or cultural) of illness
- Additional practical complexities exist for ethnic minority groups, including those associated with obtaining death certificates; assembling family in a timely way; possibility of large numbers wishing to visit; misunderstandings due to language (in diagnosis and prognosis situations).

Dissemination, Outputs and Impact

Our Sawubona ("I see you") <u>video</u> speaks about the importance to people of being known and has been well received at national conferences.

We have undertaken a programme of engagement with ethnically diverse local communities to discuss their awareness about palliative and hospice care and learnt that would welcome:

- Opportunity to visit a hospice
- Know more about the ReSPECT form
- More discussion groups in the communities
- Leaflets in the Doctor's surgery, library
- o Talks on the radio and places of worship
- Taught in schools
- Information made available online and on social media

We are collaborating with EAVA FM and DeMontfort University to work with young people to discuss why dying matters to them and creating a jigsaw art work of their thoughts. The project was awarded funding in March 2023 for a second year by *Dying Matters*.

We are consulting with groups of people who are Muslim about the importance of the Shahadah (Declaration of faith) in their care as they are dying, supported by a small 'inclusivity grant' from the East Midlands NIHR Clinical research network.

We were awarded Impact funding by Marie Curie to take forward a 12-month project to support health professionals in working effectively with interpreters.

7. The five-year Stoneygate programme of work: June 2021-May 2026

This work and our Centre for Excellence has three themes.

- Older people and family carers
- Advanced symptom management
- Communication and decision-making

There are a number of studies that fit in these themes:

Older people

Pre-transfer clinical decision assessment:

Led by Chris Williams working with Kay Phelps and Emma Regen.

Evaluating the effects of a complex change (involving ambulance staff, specialist GPs and geriatricians) in the usual clinical care pathway for frail older people when an ambulance has been called to a care home or their own home. Recently awarded a second year of funding (£450k) by the LLR ICS as a result of findings indicating significant resource savings as well as improved outcomes for patients. Evaluation of the model is ongoing, led by the Centre for Excellence.

Understanding the varied experiences of frailty in older age with respect to ethnicity

Chris Williams is working with Professor Susan Pickard at the University of Liverpool as coapplicant on this interdisciplinary, international collaboration which commenced work in mid-2022.

Family Carers

Led by Linda Birt working with Fawn Harrad-Hyde.

Preparing for change

Exploring ideas to support family members in preparing for deterioration of loved ones in care homes. Data collection in this study is almost completed. We undertook interviews with 11 carers, 12 bereaved family members, and 11 senior care home staff. Our key emerging finding is that family carers can find planning for deterioration in their relative's health very difficult and they considered that a form of peer mentoring might help. Our findings are being shared through conferences, public involvement events and written reports are being developed. We intend to examine ways in which peer mentoring might work.

Empowering and educating family carers supporting a person at end of life Working with LOROS education department and The Carers Centre, Leicester we developed and delivered four education sessions, which were well received and are available online.

Mental health literacy of Young adult carers from minority ethnic communities Exploring and understanding how young adult carers of seriously ill relatives from ethnically diverse backgrounds recognise and seek help for their mental and emotional wellbeing. Supervised by Zoebia Islam.

PhD studentship, Chandini Subramanyam started in October 2022.

Advanced symptom management

Anticipatory medications and end of life care

Building on LOROS work with bereaved relatives undertaken in 2019 by Christina Faull,

Chris Williams and Linda Birt who are involved in a number of projects in care homes and peoples own homes.

A new information leaflet for patients and family has been developed for use across hospice, UHL and LPT services. This includes information that family carers said was important to them and which was often not told to them. It should also act as prompt for discussions about future deterioration and how to prepare for this and how to seek support and advice.

Ventilation and MND

Christina Faull works with Dr Ellie Wilson at University of Nottingham

There are two projects, one on the experiences of tracheostomy ventilation and one on decision making related to non-invasive ventilation (NIV).

Anxiety and breathlessness

Led by Christina Faull working with Lucy Bleazard and Tara Maitland.

This programme of work is scoping the potential for the novel non-pharmacological intervention of cranio-electrical stimulation to reduce anxiety. Recruitment will begin for a feasibility study at LOROS and Cynthia Spencer Hospice in Northampton in Summer 2023 (see in preparation in section 3 above).

Dr Lucy Bleazard has been appointed to a three-year NIHR Academic clinical fellowship commencing in August 2023, linked to this area of work.

Communication and Decision-Making Study

Communication and Decision-Making study

Led by Chris Williams working with Kay Phelps and Emma Regen.

This study funded by the Dunhill Trust is exploring how clinicians and patients navigate discussion about decisions that are not clear-cut. This will lead to development of a training resource for health professionals in 2025.

CRISIS study: Conversations about end-of-life readiness in Serious Illness Situations: Led by Zoebia Islam.

We are collaborating with the Kidney Lifestyle research team and the University Hospitals of Leicester dialysis services. This project will be opened to recruitment in May 2023. (see in preparation in section 5 above).

8. Grant submissions and new awards

Understanding the varied experiences of frailty in older age with respect to ethnicity: a mixed methods approach	ESRC	Awarded to University of Liverpool Chris Williams co-applicant for 36 months
P-Care study: Principles for research on ethnicity in palliative and end of life care: development of a consensus statement Principal Investigator	MRC/UKRI	Awarded to University of Hull Zoebia Islam co-applicant for 12 months
Ethnic minority communities' experience of accessing bereavement support services	NIHR Policy Research Programme	Awarded to Kings College London Zoebia Islam co-applicant for 18 months
Developing sociological theories of risk: Exploring risk work and escalation of care across professions/occupations, organisations and sectors	Foundation of Sociology of Health and Illness	Awarded Personal fellowship to Fawn Harrad-Hyde for 2 years.

Mera future ko kya? (What about my future): A qualitative, multi-methods study and linked feasibility study of South Asian young adult carers' transitions to adulthood	NIHR Research for Social Care	Through to second round Zoebia Islam co-applicant/Work package Lead 33 months
Optimising care pathways in Motor Neurone Disease for family carers: A realist evaluation.	NIHR Health and social care delivery research	Through to second round Linda Birt and Christina Faull joint PI Co-applicants Zoebia Islam, Kay Phelps and Emma Regen
Financial insecurity and psychological wellbeing in bereavement: A cross-cultural investigation	Marie Curie Research Grants	Unsuccessful Linda Birt co-applicant
LIISTEN Study: Learning from within innovative inclusive sustainable research partnerships with ethnically diverse groups to address equity in end-of-life care	NIHR Programme Development Grant	Unsuccessful Zoebia Islam Lead. Christina Faull joint Lead.

9. LOROS research bursaries for staff

The purpose of the research bursary scheme is to increase the awareness of staff about evidence-based practice and to inspire staff to improve care for patients and families. The bursary supports staff to attend conferences and research training courses, provide funding to backfill time in order that projects and ideas can be developed and also offer financial support to obtain research qualifications. In 2022-23 a bursary supported five staff to attend and present posters at the Palliative Care Congress.

Staff requested bursaries to attend in the desire to foster new ideas and knowledge to support the continued development of education programmes which will in turn support patient care and ensure LOROS education and evidence based practices department remains current. The nursing sections of the conference were pertinent to education translation as two were sessions on racial inequality in palliative and end of life care (including findings from our Thinking Ahead study delivered by Zoebia Islam) linking to the core LOROS research theme.

Attendance at conferences supported by the research bursaries allowed for the opportunity to network with peers and learn from work of other organisations.

10. Events

The Centre for Excellence launch

The LOROS Centre for Excellence in palliative and end of life care was launched in October 2022 through a virtual conference. The presentations from the event detailed below are available on https://loros.co.uk/centre-for-excellence

Christina Faull talked about *The vision for the LOROS Centre for Excellence: Research-driven improvement in end of life care* and some of our Expert Advisory Group gave inspirational talks across a number of perspectives:

Changes to the Health and Social Care Bill. Baroness Ilora Finlay, Palliative Medicine consultant and a cross bench peer in the House of Lords;

Putting patients at the centre of care. Roy Lilley, writer, broadcaster and commentator on the NHS. Founder of the Academy of fabulous stuff;

Influencing professionals to provide better care at the end of life: Role of the General Medical Council. Sue Carr, Renal Consultant in Leicester and Deputy Medical Director for the General Medical Council.

Being the voice: The role of patients and the public. Ruby Bhatti patient, carer and research champion for the National Institute of Health Research.

The Collaboration with the University of Leicester was highlighted by Rob Parkinson CEO of LOROS and Tom Robinson Head of the College of Life Sciences at the University in *Our* aspirations: Working together to drive research-led improvements in care.

The LOROS Annual open lecture

This year's lecture was delivered by Dr Laura Green, lecturer and programme director in nursing at University of Manchester, *They talk to me like I don't know my own body* focused on Laura's PhD project which explored iatrogenic suffering in older people caused by the system, and professionals in hospitals. Over 100 people registered for the lecture which was attended by 55 health care professionals, volunteers, students, and members of the public either in person or on-line.

Annual East Midlands research and audit event

This virtual event was attended by 78 delegates and showcased projects that are current and completed in the East Midlands. The headline speaker was Mel Waghorn, the project manager for the CHELsea II study opening at LOROS and three other Hospices in the East Midlands. Feedback suggested that this was the best yet.

Masterclass

Working with ethnically diverse patients in thinking ahead about deterioration, medical treatments and end of life care planning

Zoebia Islam, delivered this masterclass which was attended by both LOROS staff and health care professionals working in local organisations.

Sawubona: Equity in Palliative Care for All Research Forum

We initiated and led this National Forum for researchers working to improve end of life care for people from minority ethnic background. Zoebia Islam is the Chair and Co-ordinator and we provide the administrative support.

Virtual workshops on Community Palliative Care and Frailty

We have delivered researcher-led events to support dissemination of research about frailty to Primary Care professionals: two lunchtime seminars for primary care (each attended by around 50 people) and two half-day sessions for GP trainees across LLR. These events have covered responding to deterioration, advance care planning and ReSPECT form, rational prescribing in frailty and supporting people who are dying in the community. Building from these events, we are supporting the design and delivery of a 'spiral' training programme for GP trainees which will provide ongoing development throughout their training.

11. Conference Presentations

Date	Conference	Person	Title
Sept 2022	Australasian College of Paramedicine International conference	Dr Fawn Harrad-Hyde	"In between a rock and a hard place": Care home staff perceptions of balancing risks during resident transfer decisions.
Oct 2022	European Association of Palliative Care	Dr Zoebia Islam	Sawubona! Supporting Health Care Professionals to Make End of Life Care Accessible for All
Nov 2022	Hospice UK	Dr Zoebia Islam	Race equity in palliative care- moving Forward: Steps on our journey
Feb 2023	Marie Curie Research Conference	Dr Linda Birt and Dr Fawn Harrad-Hyde	Preparing for Change. Empowering and educating family.
Feb 2023	Nottingham Palliative Care Society	Dr Zoebia Islam	The LOROS Thinking Ahead study findings
March 2023	Palliative Care Congress	Dr Zoebia Islam	Provocations of privilege and the end of life care for those from minoritised communities – How can we be the better specialty?

12. Publications

Birt, L, Charlesworth, G, Moniz-Cook E, Leung P, Higgs P, M Orrell, Poland F. "The Dynamic Nature of Being a Person": An Ethnographic Study of People Living With Dementia in Their Communities, The Gerontologist, 2023;, gnad022, DOI: https://doi.org/10.1093/geront/gnad022

Harrad-Hyde F, Armstrong N, Williams C. Using advance and emergency care plans during transfer decisions: A grounded theory interview study with care home staff. Palliative Medicine. 2022;36(1):200-207, DOI: https://doi.org/10.1177/02692163211059343

Faull C, Pilsworth A, McEvoy K, Hughes H, Patterson A. A mixed methods exploratory study of family experiences of anticipatory injectable medicines at home: "It's a really good idea but it's just implementing it." 2022, DOI: https://doi.org/10.1101/2022.06.29.22276695

Birt L, Lane K, Corner J, Sanderson K, Bunn D. Care-home Nurses' responses to the COVID-19 pandemic: Managing ethical conundrums at personal cost: A qualitative study. Journal of Nursing Scholarship. 2022, DOI: https://doi.org/10.1111/jnu.12855

Oliver D, Baker I, Domenico Borasio G, Cras P, **Faull C**, Hepgul N, Lorenzl S, Stockdale C, de Visser M, Vanopdenbosch L, Voltz R & Veronese S. The involvement of palliative care with neurology – a comparison of UK, Switzerland and Italy, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2023;24:3-4, 256-262, DOI: https://doi.org/10.1080/21678421.2022.2136993

Harrad-Hyde F, Williams C & Armstrong N. Hospital transfers from care homes: conceptualising staff decision-making as a form of risk work, Health, Risk & Society, 2022;24:7-8, 317-335, DOI: https://doi.org/10.1080/13698575.2022.2133094

Wilson E, Lee J-S, Wenzel D, **Faull C**. The Use of Mechanical Ventilation Support at the End of Life in Motor Neurone Disease/Amyotrophic Lateral Sclerosis: A Scoping Review. Brain Sciences. 2022; 12(9):1162. https://doi.org/10.3390/brainsci12091162

Parry R, Whittaker B, Pino M., **C Faull**. et al. RealTalk evidence-based communication training resources: development of conversation analysis-based materials to support training in end-of-life-related health and social care conversations. BMC Med Educ 2022, 637, DOI: https://doi.org/10.1186/s12909-022-03641-y

Harrad-Hyde F, and others, 'Weighing up risks': a model of care home staff decision-making about potential resident hospital transfers, Age and Ageing. 2022;51(7), DOI: https://doi.org/10.1093/ageing/afac171

Chapman-Wright J, Parnell S-A, **Birt L**, Bunn D, Lane K. Perspectives: Nurses in care homes as advisors in research: benefits for all? Journal of Research in Nursing. 2022;27(4):401-405m DOI: https://doi.org/10.1177/17449871221103839

Wenzel D, Bleazard L, Wilson E, **Faull C** et al. Impact on staff of providing non-invasive advanced respiratory support during the COVID-19 pandemic: a qualitative study in an acute hospital. BMJ Open 2022;12:e060674, DOI: https://doi.org/10.1136/bmjopen-2021-060674

Long-Sutehall T, Madi-Segwagwe B.C., Hurlow A., **Faull C**. et al. The potential for eye donation from hospice and palliative care clinical settings in England: a retrospective case note review of deceased patients' records. Cell Tissue Bank 24, 341–349 (2023), DOI: https://doi.org/10.1007/s10561-022-10036-2

Young C. A., Ealing J, McDermott C. J., Williams T. L., Al-Chalabi A, Majeed T, Talbot K, Harrower T, **Faull C**, Malaspina A, Annadale J, Mills R. J., Tennant A., & On behalf of the TONiC Study Group. Measuring disability in amyotrophic lateral sclerosis/motor neuron disease: the WHODAS 2.0-36, WHODAS 2.0-32, and WHODAS 2.0-12, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. 2023;24:1-2, 63-70, DOI: https://doi.org/10.1080/21678421.2022.2102926

Young C. A., Ealing J, McDermott C. J., Williams T. L., Al-Chalabi A, Majeed T, Talbot K, Harrower T, **Faull C**, Malaspina A, Annadale J, Mills R. J., Tennant A., & On behalf of the TONiC Study Group. Prevalence of depression in amyotrophic lateral sclerosis/motor neuron disease: multi-attribute ascertainment and trajectories over 30 months, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. 2023;24:1-2, 82-90, DOI: https://doi.org/10.1080/21678421.2022.2096410

Wilson E, Turner N, **Faull C**, et al. Understanding living with tracheostomy ventilation for motor neuron disease and the implications for quality of life: a qualitative study protocol. BMJ Open 2023;13:e071624, DOI: https://doi.org/10.1136/bmjopen-2023-071624

Rose L, Thaventhiran T, Hobson E, **Faull C**. et al. Digital peer-to-peer support programme for informal caregivers of people living with motor neuron disease: study protocol for a multicentre parallel group, single-blinded (outcome assessor) randomised controlled superiority trial. Trials 24, 119 (2023), DOI: https://doi.org/10.1186/s13063-023-07124-3