

Academic Unit of Palliative Care Annual Report



2023/24

in partnership with

UNIVERSITY OF LEEDS



Always caring

• UNIVERSITY TEACHING HOSPICE •



Contents

Contents

2

Executive Summary

3 - 4

Introduction and AUPC Overview 2023-24

5 - 7

Learning and Teaching

8 - 19

External Education Provision

9 - 14

Clinical Placements

15 - 16

Internal training to St Gemma's Hospice Staff

16 - 19

Research

20 - 25

University of Leeds

21 - 23

St Gemma's Hospice

23 - 25

Evidence Based Practice

26 - 27

Contact Details

28

Appendix 1: Papers Published in Peer Review Journals

29 - 35



Executive Summary

The Academic Unit of Palliative Care (AUPC) presents its Annual Report for 2023/24, summarising a year of significant achievements in education, research, and evidence-based practice. The AUPC continues to be a recognised centre of excellence in palliative care, advancing its mission to improve care for those approaching the end of life through integrated research, teaching, and clinical practice.

Education and Training

In 2023/24, the AUPC Education team delivered high-quality educational programmes to over 1,013 health and social care professionals, alongside St Gemma's Hospice staff. This included the development and implementation of new programmes and the enhancement of existing ones to meet emerging needs. The approach combined virtual, face-to-face, and hybrid learning formats, maximising accessibility and flexibility.

Key educational initiatives included the expansion of Advanced Communication Skills Training (ACST) and specialised End of Life Care training, which received outstanding feedback from participants. Clinical placements saw a significant increase, with 156 students hosted, reflecting both national and international interest.

Research Achievements

The AUPC's research efforts, conducted in collaboration with the University of Leeds and St Gemma's Hospice, continued to make a substantial impact in the field of palliative care. Over 50 papers were published in high-quality peer-reviewed journals, and the unit secured substantial external grant funding, bringing the total research portfolio to £17.6 million.

Notable projects include AI4HOPE, focusing on artificial intelligence in dementia care, and studies on social determinants of health in end-of-life care.

The research team also expanded its capacity by appointing new staff and developing the Leeds Deepend Network to build research infrastructure in underrepresented areas. St Gemma's Hospice further embedded research into its practice, appointing a dedicated Research Practitioner to enhance research culture and involvement.

Evidence-Based Practice

The Evidence-Based Practice (EBP) Group at AUPC played a pivotal role in ensuring clinical decisions are informed by the latest evidence. This multidisciplinary group meets monthly to update clinical guidelines, oversee audits, and foster a culture of enquiry and innovation. The group's work has been instrumental in integrating research findings into daily practice, thereby enhancing patient care quality.

Looking Ahead

Moving forward, AUPC aims to continue its growth and development in alignment with its refreshed strategy for 2024-2028. This strategy focuses on expanding impact, fostering connections, and extending reach through continued innovation in education, research, and clinical practice.

Conclusion

The AUPC Annual Report 2023/24 highlights a year of significant progress and achievement across its core areas of education, research, and evidence-based practice. By advancing its strategic objectives and fostering a culture of excellence, AUPC is well-positioned to continue leading improvements in palliative care for those approaching the end of life.

For more detailed insights into our programs, research, and future plans, please refer to the full report.



Introduction and AUPC overview



Introduction

We are pleased to present the Academic Unit of Palliative Care (AUPC) annual report for 2023-24 (April 2023 to end of March 2024) which summarises our achievements throughout the year.

The Academic Unit of Palliative Care (AUPC) consists of three areas: Research; Learning and Teaching; and Evidence into Practice. The AUPC has continued to grow and develop over the last year and has consolidated its position as a centre of excellence and an outstanding model for improving care of those approaching the end of life through integrated research, teaching and application into clinical practice.

In 2023 The Senior Academic Leadership Team developed and is now implementing a refreshed AUPC strategy for the period 2024-2028. This strategy outlines and proposes a vision and direction of travel for the AUPC and identifies a set of strategic objectives over the next 4 years. This strategy dovetails with the overall Hospice Strategy 2018-28 and its pillars of Impact, Connect and Extend.

Sharing our knowledge across the globe!

We recently welcomed a team from the Ministry of Health in Singapore, consisting of senior healthcare professionals who are responsible for developing community palliative care services in the country. The team were keen to learn about models of Palliative Care in Primary Care settings, and how to educate staff with the right level of knowledge and skills to look after patients with chronic progressive and advanced illness and illness with complex needs.

From this visit we have formed some good links and the team felt that the information they received was extremely useful to take back to inform the palliative care service development in Singapore.

Trish Stockton

Head of Education (AUPC)



Academic Unit of Palliative Care

Mission Statement

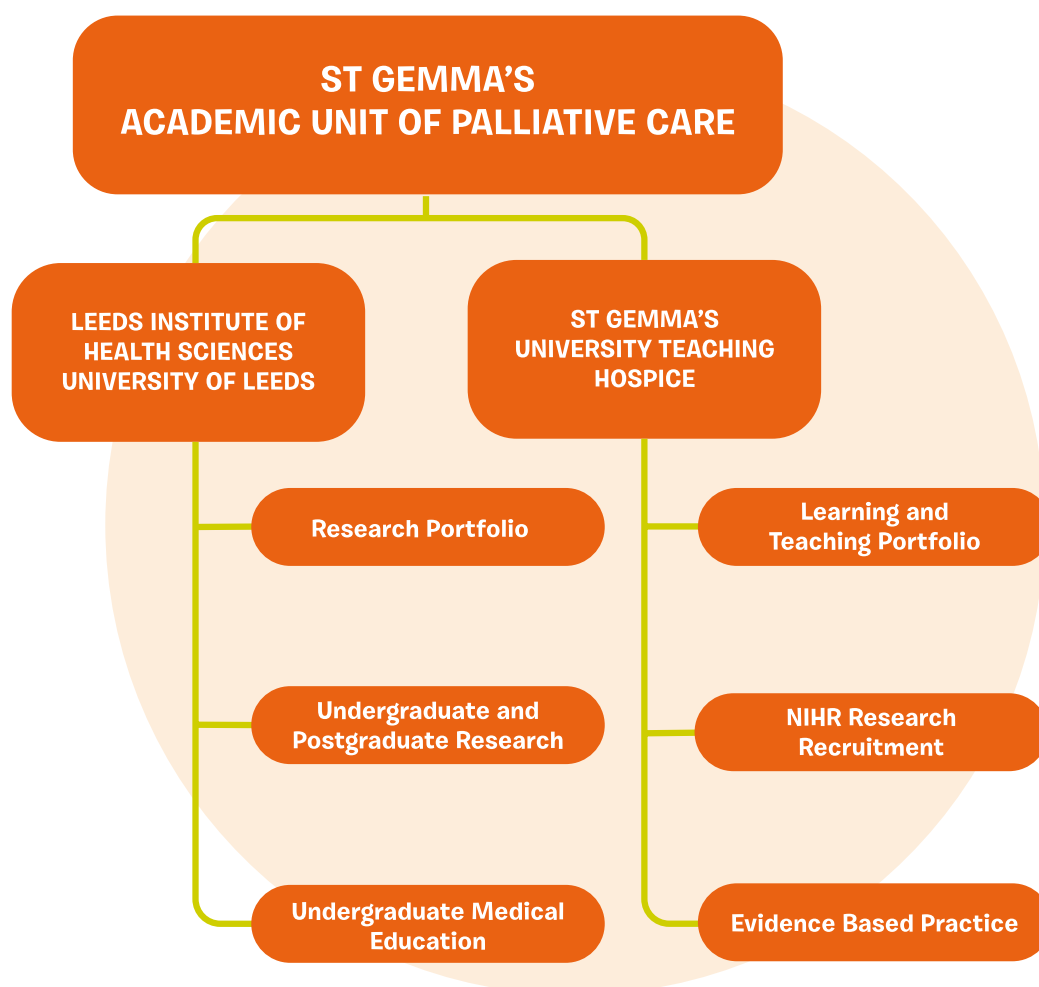
The Academic Unit of Palliative Care (AUPC) aims to be recognised internationally as a centre of excellence and an outstanding model for improving care of those approaching the end of life through integrated research, teaching and clinical practice.

Our work is guided by our values:

- ♥ **Respect and value patients**, carers, staff and all those we work with
- ♥ **Innovate and integrate** with local clinical practice
- ♥ **Inspire and support continual development and sharing of knowledge**
- ♥ **Build capacity to ensure a sustainable academic unit**
- ♥ **Be responsible and accountable for the standard of our work**

Academic Unit of Palliative Care Structure

We link academic and clinical partners and are physically located on two sites: the Leeds Institute of Health Sciences, University of Leeds and St Gemma's University Teaching Hospice. This underpins our commitment to integrated clinical academic practice.



Learning and Teaching



Introduction:

The Education team have continued to deliver a comprehensive programme of high quality education to 1,013 health and social care professionals and also St Gemma's staff in 2023-24. This has been a period of embedding new programmes, reviewing and updating existing programmes and developing some new education after requests received from various organisations and forming new collaborations. It has also been a time of reviewing the learning and teaching objectives in line with the overall AUPC strategy, with some new exciting developments in the future.

Over the last 2 ½ years a large proportion of the external training has been delivered virtually but we have reintroduced some face-to-face training and a hybrid approach where there is a mixture of virtual and face to face learning, which participants seem to really benefit from.

We continue to deliver clinical placements and have seen an increase in the demand for elective placements from across the country and internationally.

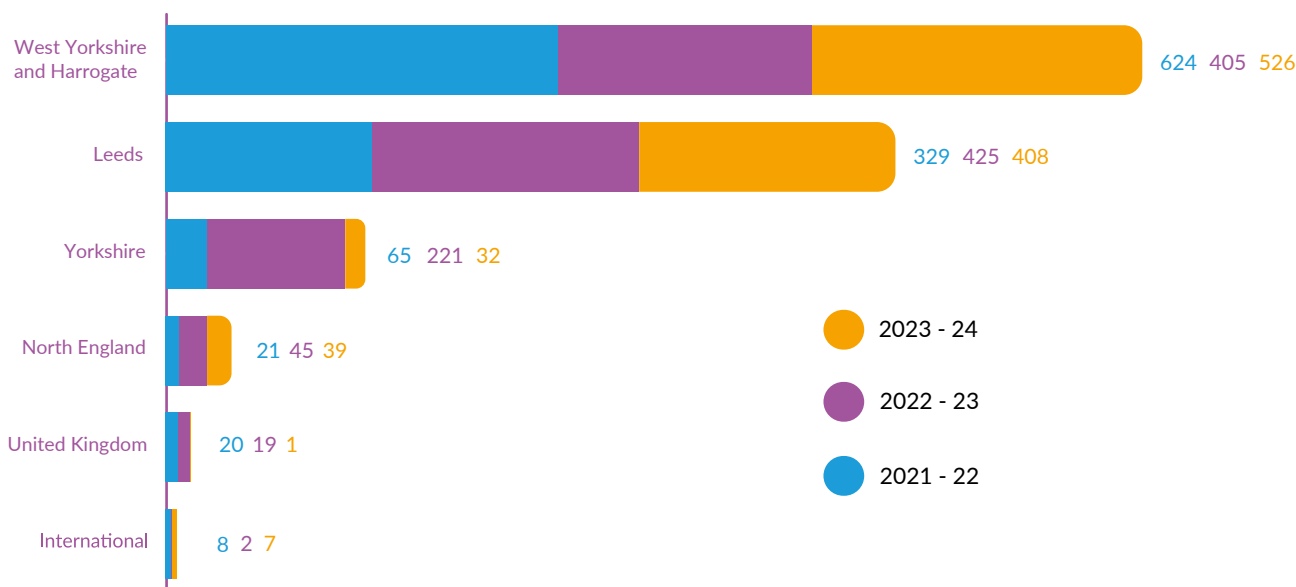
This section covers the following areas:

- ♥ External Education Provision
- ♥ Clinical Placements
- ♥ Internal training to St Gemma's Hospice Staff

External Education Provision

Geographical areas who access training:

This graph shows the breakdown of the different geographical areas accessing training for external training provision over the last 3 years. West Yorkshire and Harrogate (excluding Leeds), continues to be the main area where people access training from.

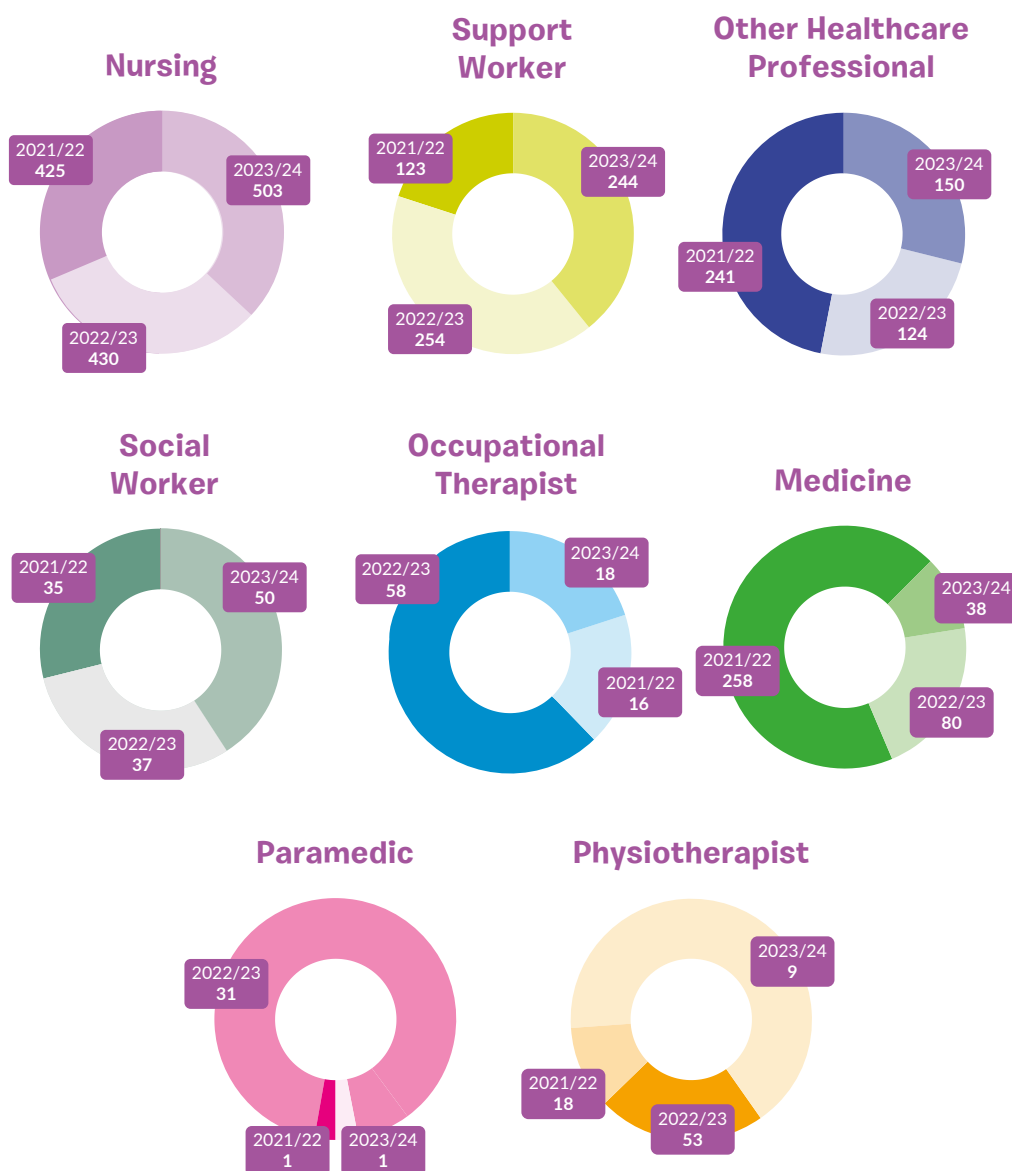


Courses Delivered

We deliver a range of education study days and programmes in key areas of palliative and end of life care including:

- ♥ Communication skills
- ♥ End of Life Care
- ♥ End of Life Care and Dementia
- ♥ Advance Care Planning
- ♥ Assessment and Symptom Management
- ♥ Bereavement and Loss

There are a range of Health and Social Care Professionals who access the external training programme. These graphs show the different professionals over the last 3 years. Nursing is consistently the main profession accessing training. Other Health and social care professionals include – peer navigators, podiatrists, speech and language therapists, senior research fellows, administrators and EOLC Doulas. The feedback we received indicated that the reduction in numbers of medical staff during 2023-24 was due to the number of national doctor's strikes and the challenge for them to attend training over this period of time.



2023-2024 external provision in more detail:

Communication Skills Training:

- ♥ **Advanced Communication Skills Training (ACST)** – This is a core programme delivered on a monthly basis. The programme is delivered virtually and face-to-face. The training is in high demand and continues to receive extremely good evaluations with 100% of people saying that would recommend this course to their colleagues.
- ♥ **Harrogate District Foundation Trust (HDFT)** – This has included a bespoke session for 80 Podiatrists in training on breaking bad news and also an ongoing training programme in communication skills commissioned by HDFT for their staff in hospital and community settings. This training also includes a half day training session on Advance Care Planning.
- ♥ **Leeds Community Healthcare (LCH)** – there are 2 key areas in an ongoing training programme for LCH staff:
 - ReSPECT Communication Skills Training – to senior clinicians who are ReSPECT signatories. This compliments the Planning Ahead training that we contribute to delivering as part of the Leeds Palliative Care Network.
 - End of Life Communication Skills Training for Band 5 Clinicians

“Thank you so much for presenting at our team together day last week. Your talk was the highlight of the day and when I got to work the next day the staff were still talking about it. I really appreciate you taking the time and effort to deliver this for our team.

Feedback from a Lecture on Breaking Bad News that was delivered face to face to Podiatrists.

“Absolutely fantastic course. Only wish it was mandatory as there are sadly many professionals I work with who would benefit from this course. I think everyone has something to take away from this course.

The very next day I started to implement the learning I gained in both my professional life and personal. I will always remember this training it has taught me so much.

Feedback from a delegate on the Advanced Communication Skills Training.

End of Life Care (EOLC) Training:

The EOLC training comprises of four key areas:

1. Difficult conversations at end of life
2. Supporting personalised and advance care planning discussions at end of life
3. Care of patients in last weeks and days of life
4. Bereavement and loss (including self-care)

It has been delivered to the following areas:

- ♥ **Health Support Workers in West Yorkshire and Harrogate** - St Gemma's AUPC obtained funding from the WY&H Support Staff Workforce Development Funding to provide End of Life Care training for Health Support Workers across West Yorkshire and Harrogate.
- ♥ **End of Life Care Training for Social Care and Support Workers, Leeds City Council (LCC)** - LCC commissioned St-Gemma's Hospice AUPC to develop and deliver an ongoing end of life care training programme for their Social Care and Support Workers who care for clients in their own homes and in care homes. The training comprises of a full face to face introduction to palliative care session and EOLC webinars as refresher training.

End of Life Care and Dementia

The Lecturer in Palliative Care in the Education team is also the Dementia Lead for the hospice and provides comprehensive training in this key area of end of life care.

- ♥ **End of Life Care and Dementia Study day** – This is delivered by the lecturer in palliative care and also the Liaison Psychiatrist for St Gemma's Hospice, based at LYPFT. There are two further study days planned for June 2024 and October 2024.
- ♥ **End of Life and Dementia for Leeds City Council** – this is a virtual training which is incorporated with training that LCC deliver to their staff about Dementia Awareness and Person Centred Dementia Care.

“Very educational, opened my eyes to things I had not previously thought about. Will definitely take this back to the team. Thank you.

Feedback from a delegate who attended the End of Life Care for People with Dementia study day in October 2023.

”

Palliative Care Programmes

These are longer programmes delivered/ supported by the education team on an ongoing basis over the year and are either face to face, virtual or hybrid:

- ♥ **Principles of Palliative and End of Life Care Programme** – This is a new programme developed by the team and is a level 4/5 (2nd/3rd year degree equivalent) 12 week hybrid programme, aimed at health and social care staff. It is fully funded by West Yorkshire Combined Authority. We have run 2 full cohorts, with another 2 cohorts planned in 2024-25.
- ♥ **The Introduction to Palliative and End of Life Care Programme** - This is also a new programme which has been developed and is targeted at Health and Social Care Professionals who are new to palliative and end of life care or who want to refresh their knowledge. This is fully funded by West Yorkshire Combined Authority. The 7 week hybrid programme taught at an equivalent to a level 3 qualification ('A' level equivalent). We delivered one programme in 2024 and 2 further programmes are planned for 2024-25. The classroom days are being held in Kirklees and in Wakefield to support the attendance of participants from these areas who may not otherwise access face to face training in Leeds. We are teaching this with other palliative care providers from these areas.
- ♥ **European Certificate in Essential Palliative Care (ECEPC)** – This is a nine-week, distance-learning, multi-professional programme, originally developed at Princess Alice Hospice, is offered twice a year in the St Gemma's AUPC.
- ♥ **CNS (Clinical Nurse Specialist) Regional Programme** – The Specialist Palliative Care CNS development is a programme funded by Health Education England (now NHS England) and hosted through the ECHO hub in collaboration with the region's CNS group. We have run a total of 5 programmes for Palliative Care CNSs across West Yorkshire & Humber, North East & Cumbria and deliver one programme per year.

Other Education/ study days:

Yorkshire Regional Palliative Medicine Learning Group – This quarterly run education session is hosted and organised by the AUPC and is attended by consultants, specialist trainees, doctors and senior nurses from across Yorkshire and the Humber. As a result of the pandemic, meetings were moved from face-to-face to virtual, but is now being delivered as a hybrid model.

Ethical Issues in Palliative and End of Life Care Study Day – Dr Janet Holt is an Associate Professor in Healthcare Ethics in the School of Healthcare, University of Leeds, with extensive experience of teaching and researching healthcare ethics and nursing philosophy. Dr Holt delivered a virtual training session on Ethical Issues in Palliative and End of Life Care in April 2023.

Symptom Management Study Days – We have delivered three virtual Symptom Management Study days for Health and Social care professionals. The sessions covered were; Pain, Gastrointestinal Symptoms and Palliative Care Emergencies and Refractory Symptoms.

Bereavement & Loss training for Solicitors – A solicitor's company requested bereavement training for their Probate teams. The St Gemma's Bereavement Team carried out a session in January 2024 to 6 people. The evaluations showed that the team felt the training would help them in their roles and that it was extremely useful. We have planned a further session with more of the team in October 2024.



“ **Recommend this course to any colleague working in the field – really informative. Led by knowledgeable, kind, compassionate staff and a good way of meeting new people.** ”

Feedback from a delegate on the Introduction to Palliative and End of Life Care Programme

“ **This was a fantastic course. I just want to say a special thank you for putting together such a great day. We had a fantastic group and I always enjoy working with colleagues from the wider MDT as I think this greatly adds to our learning experiences. Thank you.** ”

Feedback from a delegate on the Symptom Management Study days.

Training in collaboration with the Leeds Palliative Care Network

St Gemma's AUPC hosts the LPCN Education team which consists of the LPCN Clinical Practice Educator and Education administrator. This team supports the development of training and collaborative working across Leeds. St Gemma's staff have supported the LPCN training by co-facilitating in the following areas:



**Leeds Palliative
Care Network**

Planning Ahead (ReSPECT) Training – this ongoing training involves training senior clinicians in both hospice, Primary Care and Leeds Community Health Care Trust, to be new ReSPECT signatories or updating those who are already signatories.

Homelessness Education - The Homelessness project began in 2020 supported by a multiagency steering group through Leeds. As part of this project it was recommended that a homelessness and vulnerably housed palliative care education programme was developed. A pilot day took place on the 11th of November 2022, delivered by St Gemma's AUPC. The course was developed for non-healthcare frontline homelessness and inclusion workers throughout Leeds. The LPCN have provided funding for a further 6 education days. Five of the education days have been delivered from September 2023 – July 2024 for workers across Leeds. The final education day in September 2024 will be offered to workers across West Yorkshire.

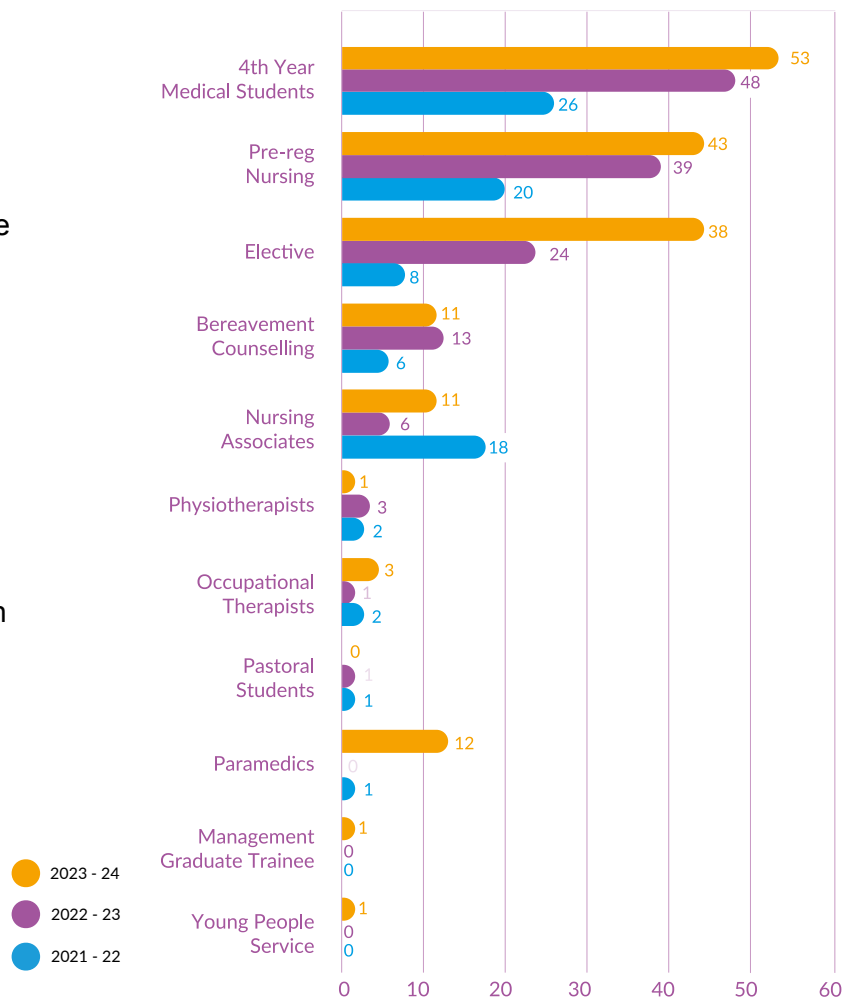
Words used by the professionals accessing the different training sessions:

Fantastic Enjoyable Useful
Friendly Excellent Detailed
Quality Thought-provoking
Approachable Knowledgeable
Interesting Comprehensive
Helpful Informative Relevant

Clinical Placements

Clinical placements at St Gemma's Hospice offer a unique and invaluable experience for healthcare students and professionals in palliative care. These placements provide an opportunity to develop not only technical skills but also critical interpersonal skills such as empathy, communication and holistic care. The hospice has a significant role in teaching students about comfort, dignity and quality of life for patients with life-limiting illnesses.

This graph shows the range and numbers of students/ placement we have had at the hospice over the last 3 years.



- ♥ We have hosted a total of 156 students on placement in 2023-24.
- ♥ We have extended the length of time in a year where we take 4th year medical students in response to take more medical students as there has been a higher intake into medical training.
- ♥ We have also increased the number of pre-registration nursing students on placement in response to a higher number of students on the programme.
- ♥ We have seen an increase in the demand for elective placements from across the country and internationally.
- ♥ We now take 3rd year Paramedic students on placement in the community team.

We receive extremely positive feedback from students about their time at the Hospice, from administrative staff providing a welcome and supporting throughout the placement, to the clinical staff who offer the students opportunities to practice their skills. This is testament to the year-round work of many individuals, teams, and mentors involved in planning and hosting the placements and the way they teach, assess and support our students.

“Hospice placement was really useful and helpful to my learning, all of the staff were friendly too. I wish we had more time in hospice care than the 4 days allocated.

Feedback from a Year 4 Medical Student

“

St Gemma's is a great place for hospice placement! The doctors are lovely and very supportive to our learning.

Feedback from a Year 4 Medical Student

”

“

The staff were all incredibly friendly and welcoming. I had a fantastic time at St Gemma's. When patients were discussed in meetings, doctors would check my understanding of aspects of the case afterwards. One of the consultants was great at picking out which aspects were particularly relevant for 4th year exam knowledge. I would highly recommend this placement to my peers.

Feedback from a Year 4 Medical Student

”

Internal training to St Gemma's Hospice Staff

The Learning and Teaching department supports Hospice staff with continued professional development by delivering a comprehensive internal training programme and approving study leave to attend relevant external study.

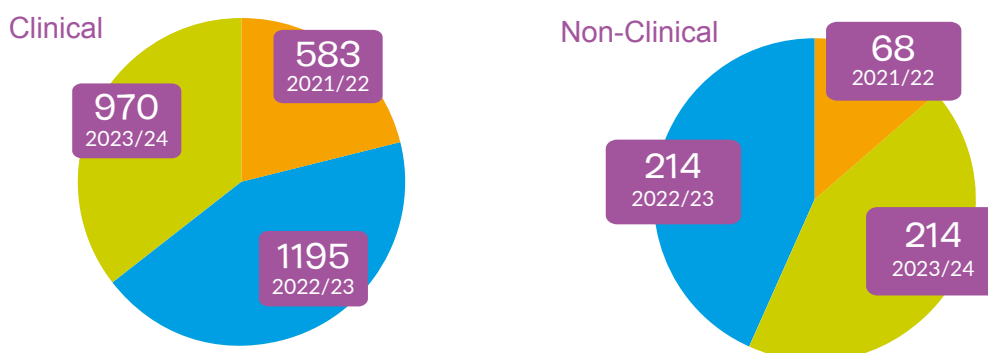
Education is delivered face to face, hybrid and also via the **Learning Management System (LMS)**, where mandatory training modules and general training are carried out.

There are plans to upgrade the Learning Management System to a Learning Experience Platform over this next year which will allow a more personalised approach to learning according to role, learning style and previous learning completed. This will include a review of mandatory training modules and how these are delivered.



General internal training

All St Gemma's staff can access the comprehensive internal training programme. The Hospice currently has approximately 210 non-clinical staff and 160 clinical staff. This chart shows the overall number of attendance's on the internal training programme over the last 3 years.



Internal training

In 2023-24 the internal training programme has comprised of the following:

Clinical Skills Training:

- ♥ AED (automated external defibrillator), Cardiopulmonary Resuscitation, and Anaphylaxis
- ♥ Practise Assessors or Practice Supervisors (in line with NMC Standards for Student Supervision and Assessment)
- ♥ HCA band 3 mentorship training
- ♥ PPE (LV1), Fit Testing (LV3), Hoods Training (LV3)
- ♥ Clinical Updates (including SHAM, IV & CL, Blood Transfusion)
- ♥ Clinical Priority (Falls, Pressure Area Care, Management Terminal Agitation, Management Nausea and Vomiting)
- ♥ Venepuncture and Cannulation
- ♥ Catheterisation training
- ♥ Single Nurse Administration of Drugs (SNAD)
- ♥ Symptom Management Breathlessness and Fatigue
- ♥ Welcome sessions to Student Placements (including PPE training and FIT test)
- ♥ HCA Training Day
- ♥ Community Education Programme
- ♥ A Guide to Nutrition
- ♥ Tracheostomy study days
- ♥ Ward based teaching sessions
- ♥ Wellbeing sessions on IPU Team away days
- ♥ Peer support sessions for clinical supervision
- ♥ Suctioning Training for RNs and HCAs

Digital Skills Training

- ♥ IT Skills Pathway – offering a range of Digital Skills training to staff which includes Microsoft Excel, Word, Outlook etc. The Skills Pathway also allows staff to assess their current skills and recommends relevant e-learning modules for completion.

- ♥ Digital Skills Workshops, including Outlook, Word, Excel and OneNote

Induction sessions:

- ♥ Clinical induction (introduction to palliative care, spirituality & resilience sessions)
- ♥ Essential Information Induction Session
- ♥ Hospice Corporate Induction

Communication skills training:

- ♥ Advanced Communications Training
- ♥ Band 5 Communications Training
- ♥ HCA Communications Training

Other training:

- ♥ Bereavement and Loss Awareness Training
- ♥ Fire Marshall training
- ♥ Safe Moving and Handling
- ♥ Finance Training for Managers
- ♥ Hospice Strategy, Governance and Assurance

Excellent training session, all the managers will really benefit from it

Feedback from a participant on the 'Bereavement and Loss' session

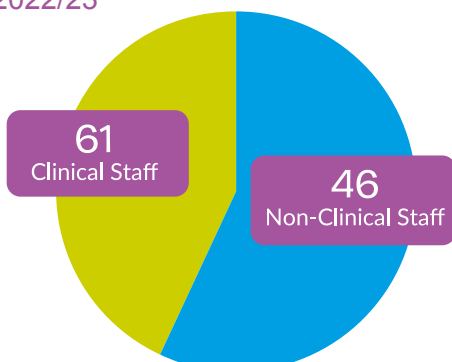
The whole day was excellent...everyone taught in a really knowledgeable and engaging way, definitely experts in their field.

Feedback from a participant on the Symptom Management Study Day

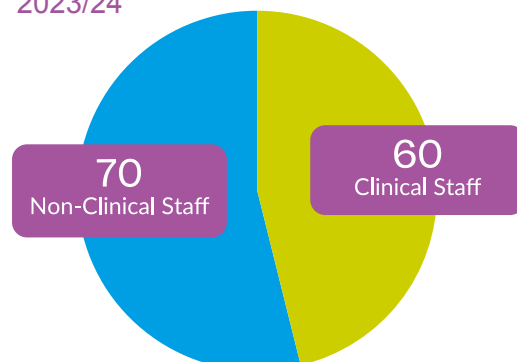
St Gemma's staff accessing external study and training over the last 2 years:

St Gemma's staff also have a training budget to attend external study days.

2022/23



2023/24



“ This was a great opportunity for personal growth and to hone in on all of my current skills and how I am using them.

Staff member who attended the Springboard Development Programme ”

“ I have learnt new skills when communicating...I have had various conversations with staff throughout the hospice which has sparked an interest and people are now interested in attending the next study day.

Staff member who attended the 'Deaf Awareness' Training ”

Apprenticeships

The hospice pays an apprenticeship levy which is a tax is paid by employers with a payroll of more than £3 million per year. It is charged at 0.5% of our wage bill. This fund is accessed by the hospice to pay for apprenticeship training costs. The government adds a further 10% extra to the funds.

The apprenticeships which have been undertaken in this period are:

- ♥ Fundraiser level 3 - 2 members of staff
- ♥ Team Leader/ Supervisor level 3
- ♥ Data Technician level 3
- ♥ Health Support Worker level 2

Over the next 12 months there are planned apprenticeships in the following areas:

- ♥ Health Support Worker Level 3
- ♥ Trainee Nursing Associate Level 4 – 2 members of staff
- ♥ Leadership Level 7



Research



University of Leeds Academic Unit Research Programme

The research team continues to make an internationally leading contribution to the research field. During the last 12 months we have published over 50 papers in high quality peer reviewed journals. As a team we have reaped the rewards of a period of intensive grant writing, securing external research grant income from the UK National Institute for Health Research (NIHR) EU and charities (YCR, Marie Curie). The Palliative Care Research Group now has a current £17.6 million portfolio of research (In 2021 our portfolio of research was £3.1m). We have established the Leeds Deepend Network and appointed a project manager Aaishah Aslam to lead the network and build research infrastructure in GP practices based in the most deprived areas of the city. With several grants due to start in the Autumn the team is set to expand from 12 to 15 members.



April 2023 – March 2024

Current Grants				
New grant income during this period:				
Title	Funder	Investigators	Amount	Dates
AI4HOPE: Artificial intelligence-based health, optimism, purpose, and endurance in palliative care for dementia	Horizon Europe	Co-I Matthew Allsop PI Professor Abdulhamit Subasi at the University of Turku	£6.1M	2024 – 2028
The Association of Social Determinants of Health in Decision Making at the End of Life: A Retrospective Observation Cohort Study	BMA	Joint-PI Matthew Allsop	£65,000	2023 – 2025
NIHR Palliative and End of Life Care Policy Research Unit	NIHR		£3m	January 2024
Research applications – outcome pending				
HOPSCOTCH Helping Optimise Primary Care Support During Transition From Children's Hospice Care	NIHR HSDR	Lucy Ziegler and Sarah Mitchell Joint Investigators	£898,000	
EPIC- PC Equitable Palliative care In the Community through Primary Care (EPIC-PC): a realist study to propose a new integrated neighbourhood team approach to palliative and end of life care	NIHR HSDR	Lucy Ziegler and Sarah Mitchell Joint Investigators	£1,086,598	
Intervention to optiMise Palliative caRe for peOple with liVed Experience of homelessness (IMPROVE)	NIHR HSDR	Lucy Ziegler	£814,478	

Equitable Care for All Ethnicities (ECAE): Improving data collection on ethnicity and religion within palliative care settings	Marie Curie	PI: Gemma Clarke Successful at Stage 1 EOI of Marie Curie Research Grants Scheme 2023.	£127,524.90	
Ensuring equity for ethnically diverse and minoritised unpaid and family carers: cultural adaptation and feasibility testing of the Carer Support Needs Assessment Tool Intervention	NIHR	Co-applicant: Gemma Clarke, PI Professor Jonathan Koffman, University of Hull Successful at Stage 1 EOI. Research for Patient Benefit (RfPB) Programme: NIHR206573	£249,903.00	
RfPB Under-represented disciplines call April 2024: COMFORT study	NIHR	Carole Paley Matt Mulvey	£197,000	
Grants ongoing				
AI4HOPE: Artificial intelligence-based health, optimism, purpose, and endurance in palliative care for dementia	Horizon Europe	Co-I Matthew Allsop PI Professor Abdulhamit Subasi at the University of Turku	£6.1M	2024 – 2028
The Association of Social Determinants of Health in Decision Making at the End of Life: A Retrospective Observation Cohort Study	BMA	Joint-PI Matthew Allsop	£65,000	2023 – 2025
NIHR Palliative and End of Life Care Policy Research Unit			£3m	January 2024
ESRC White Rose Doctoral Training Partnership (WRDTP) 1+3 Pathway Postgraduate Studentship Award	ESRC	PI Gemma Clarke	£86,632	2023-2027
Intensive Interaction for children and young people with profound and multiple learning disabilities: INTERACT trial	NIHR HTA	Co-I L Ziegler	£1,833,312	2023-2028
Parent and professional experiences of 24/7 paediatric end of life care a mixed methods process evaluation	Marie Curie	Co-I L Ziegler	£141,644	July 2022- July 2024
Functional Loss and rehabilitation towards the end of life	NIHR	Chief Investigator Matt Maddocks Kings (Lucy Ziegler Co-I)	£99, 256	Jan 2021- July 2023
The Yorkshire & Humber Palliative Care Research Network: Addressing Inequalities Across All Ages	NIHR	Chief Investigator Prof Fliss Murtagh (Lucy Ziegler Co-I)	£99,932	Jan 2021- Jan 2024
Developing the UK Collaborative Paediatric Palliative cAre Research (CoPPAR)	NIHR	Chief Investigator Prof Lorna Fraser (Lucy Ziegler Co-I)	£96,673	2022-2023

Improving health Status and Symptom experience for people living with advanced cancer (RESOLVE)	Yorkshire Cancer Research	Co-I L Ziegler	£1,400,000	2018-2024
Electronic Palliative Care Co-ordination Systems (EPaCCS) in end of life care: evaluating their implementation and optimising future service provision OPTIMAL Care	NIHR	Chief Investigator Dr Matthew Allsop	£660,000	2020-2024
Addressing Inequalities in Access to Hospice Care	ESRC	Co-I L Ziegler	£79,288	2019-2024
Cancer pain-assessment Toolkit for use in routine oncology outpatient services: a multi-centre cluster randomised feasibility trial CAPTURE	Yorkshire Cancer Research	Chief investigator Dr Matt Mulvey	£350,540	2021-2024
Understanding access to palliative care by ethnic minority groups in the UK: with a focus on South Asians and those with refugee or asylum seeker status	Academy of Medical Sciences/ Marie Curie	Chief investigator: Dr Gemma Clarke	£111,918	
Black and Minority Ethnic pain management	Marie Curie	Chief Investigator: Dr Gemma Clarke/ Mike Bennett	£171,870	
A Delphi study of improving ethnicity research in palliative care	MRC	Gemma Clarke Co-I	£29,763	
How does choosing to fundraise in memory impact the bereavement journey? A qualitative study"	Marie Curie	Gemma Clarke Co-I.	£13,482	
Marie Curie Senior Research Fellowship focusing on a programme of work on ethnicity and palliative care	Marie Curie	Gemma Clarke Co-I.	£131,332	October 2021- October 2023

For papers that have been published in peer reviewed journals, please see appendix 1.

St Gemma's Hospice

Research Co-ordination in the Hospice

In September 2023 we appointed a Research Practitioner (RP) into a fixed term post, which has been funded by the National Institute for Health Research.' The RP's main purpose is to strengthen and develop the research capacity and capability, improve research culture, increase research involvement and facilitate the safe delivery of research activities across the Hospice. This will allow the Hospice to further embed and develop their research portfolio. Staff are involved in each research project, whether that be as a participant or to assist with recruitment.



Current Research Projects in the Hospice (September 2023 - March 2024)

Research Project Title	Short Title	Sponsor	NIHR Portfolio	Recruitment Target (for our site)	Total recruits to date (for our site)
Exploring Pathways to Optimise Care in Malignant Bowel Obstruction.	EPOC	University of Hull	Yes	10	13
Body-mind interventions and breathlessness-related distress in advanced disease: Realist interview study.	Breathlessness	Hull York Medical School	No	2	4
An international survey of continuous subcutaneous infusions: is there an unmet need for extended infusions 48 hours and beyond?	SCUTI48		No	NA	90
Why do hospice staff make referrals for specialist psychological support?		City, University of London	No	3-8	5

Networking / Research Hub

Connecting with both internal and external stakeholders is vital to improving the research culture and involvement within the hospice and across wider areas. The RP has made connections through conferences, meetings, webinars and through known contacts and through LinkedIn, including university professors, research nurses, research managers, PhD students, doctors, research engagement officers, research governance professionals, directors of research and others. Organisations / institutions that the RP has established links with include:

- Marie Curie
- Sue Ryder
- Hospice UK
- Yorkshire and Humber Palliative Care Research Network
- Yorkshire Ambulance Service
- Lincolnshire Hospitals NHS Trust
- University of Leeds
- Hull York Medical School
- University of Warwick
- Kings College London
- City University of London
- University of Huddersfield.

Literature Searches

One literature search has been conducted, focussing on Psychological and Emotional Care. 5 articles were found to be valuable for extracting useful information related to psychological and emotional care, which will hopefully be used for future research. A rapid evidence review is currently in the process of being written.

Evidence Based Practice Link

The RP is a part of the Evidence Based Practice group. Once we have participated in a research project, the researchers are asked to present their findings to the Hospice. These findings will then be presented and taught to appropriate staff and built into our standard of care. This will either be in the form of training, journal club or lunch or learn. The Evidence Based Practice group has been proven to be essential for meeting research recruitment targets due to their many links with various clinical teams across the Hospice.

Research Education and Culture

In order to improve research culture across the hospice, the RP has taken the following steps:

- ♥ Created a research section to be included in the staff bulletin.
- ♥ The RP has been proactive in connecting with staff across the hospice. She attends the wards regularly which gives the opportunity to explain to staff about research and ask any questions. RP regularly attends various meetings with different staff members across the hospice. This allows her to get to know staff and advertise studies face-to-face.
- ♥ The RP plans to make research more inclusive. Staff both clinical and non-clinical, volunteers and members of the public should have the opportunity to participate in research.
- ♥ Advertised any palliative care research conferences across the hospice, giving staff the opportunity to attend.
- ♥ RP has written a research blog, explaining the importance of palliative care research and its challenges.
- ♥ RP has also been included in the Hospice newsletter, which goes out to thousands of people. This included a brief description of RP's role, and the importance of it.



Evidence Based Practice



Introduction

Evidence based practice requires that healthcare decisions are based on the best available, current, valid and relevant evidence. It enables the development of a culture in which good decisions are made and clinicians feel confident to question and challenge practice.

The Evidence Based Practice (EBP) Group meets monthly with the aim of ensuring that our clinicians are supported to integrate latest evidence alongside clinical expertise in order to underpin safe and effective patient care. Membership of the group is multidisciplinary with representation from nurses, therapists, pharmacist, doctors, research practitioner and the newly appointed Quality and Governance Practitioner. The future vision of the group is to widen membership to ensure that all St Gemma's staff are encouraged to understand why we practice in the way we do and to promote a culture of mutual questioning and challenge.

Create a culture of enquiry and innovation

The EBP Group updates clinical guidelines, oversees the clinical audit programme and promotes evidence based practice. Representatives of the group contribute to citywide palliative care guidelines through membership of the Leeds Palliative Care Network.

Lunch and Learn

Is aimed at all Hospice staff (clinical and non-clinical). Each month a different department is asked to discuss a topic and how evidence in this area is used to improve quality and standards. For example; complimentary therapies in palliative care and end of life doulas.

Film and Book Club

The club brings staff together from the wider Hospice and encourages supportive group discussion in a safe environment. The books or films that are chosen will be on topics that we encounter in our work. An example would be the 100 year old man that climbed out of the window and disappeared.



Contact

General AUPC		
Trish Stockton	Head of Education (AUPC)	Email: trishstockton@st-gemma.co.uk Tel: 0113 218 5283
Learning and Teaching Team		
Trish Stockton	Head of Education	Email: trishstockton@st-gemma.co.uk Tel: 0113 218 5283
Jane Chatterjee	Lecturer in Palliative Care	Email: janechatterjee@st-gemma.co.uk Tel: 0113 218 5282
Caroline Brennan	Clinical Practice Educator	Email: carolinebrennan@st-gemma.co.uk Tel: 0113 218 5500 ext 2230
Emma Farrer	AUPC Administrator	Email: emmafarrer@st-gemma.co.uk Tel: 0113 218 5500 ext 2600
Tina Cosgrove	Learning & Teaching Assistant	Email: tinacosgrove@st-gemma.co.uk Tel: 0113 218 5546
Libby Foster	Training and Development Manager	Email: libbyfoster@st-gemma.co.uk 0113 Tel: 218 5500 ext. 2222
Medical Team		
Dr Mike Stockton	Chief Medical Officer and Consultant in Palliative Medicine	Email: mikestockton@st-gemma.co.uk Tel: 0113 218 5501
Dr Jason Ward	Consultant in Palliative Medicine	Email: jasonward@st-gemma.co.uk Tel: 0113 218 5294
Evidence Based Practice Team		
Dr Karen Neoh	Consultant in Palliative Medicine	Email: karenneoh@st-gemma.co.uk Tel: 0113 218 5500
Nicky Hibbert	Nurse Consultant	Email: nickyhibbert@st-gemma.co.uk Tel: 0113 218 5500
LPCN Education Team		
Leigh Taylor	LPCN Clinical Practice Educator	LPCN Education Team Email: LPCNCourses@st-gemma.co.uk
Saima Qayyum	LPCN Education Administrator	
Research		
Prof Lucy Ziegler	Professor of Palliative Care	Email: L.E.Ziegler@leeds.ac.uk
Rachel Byrne	Research Practitioner	Email: rachelbyrne@st-gemma.co.uk

Appendices



Appendix 1:

Publications 2023-24

1. Steinberg S, Hughes S, Hui H, Allsop M, Egger S, David M, Caruana M, Coxeter P, Carle C, Onyeka T, Rewais I, Monroy Iglesias MJ, Vives Martin N, Wei F, Abila DB, Carreras G, Santero M, O'Dowd E, Lui G, Tolani MA, Mullooly M, Lee SF, Landy R, Hanley S, Binefa Rodríguez G, McShane C, Gizaw M, Selvamuthu P, Boukheris H, Nakaganda A, Ergin I, Moraes FY, Timilshina N, Kumar A, Vale DB, Molina-Barceló A, Force LM, Campbell D, Wang Y, Wan F, Baker AL, Singh R, Abdus Salam R, Yuill S, Shah R, Lansdorp-Vogelaar I, Yusuf A, Aggarwal A, Murillo R, Torode J, Kliewer E, Bray F, Chan KKW, Peacock S, Hanna TP, Ginsburg O, Van Hemelrijck M, Sullivan R, Roitberg F, Ilbawi A, Soerjomataram I, Canfell K. 2023. Risk of COVID-19 death for people with a pre-existing cancer diagnosis prior to COVID-19-vaccination: a systematic review and meta-analysis. *International Journal of Cancer*.
2. Abahussin AA, West RM, Wong DC, Ziegler LE, Allsop MJ. Supporting Pain Self-Management in Patients With Cancer: App Development Based on a Theoretical and Evidence-Driven Approach. *JMIR Cancer*. 2023 Oct 9;9:e49471.
3. Millares Martin P, Allsop M, Carder P. 2023. Will medical cause of death certifications data quality improve in the UK with the new medical examiner system. *Journal of Clinical Forensic and Legal Medicine: an International Journal of Forensic and Legal Medicine*.
4. Spencer, KL., Absolom, KL., Absolom, MJ., Relton, SD., Pearce, J., Liao, K., Naseer, S., Salako, O., Howdon, DDH., Hewiso, J., Velikova, G., Faivre-Finn, C., Bekker, HL., & Van Der Veer, S. (Accepted/In press). Fixing the leaky pipe: how to improve the uptake of patient reported outcomes-based prognostic and predictive models in cancer clinical practice. *JCO Clinical Cancer Informatics*.
5. Papworth A, Bedendo A, Taylor J, Beresford B, Mukherjee S, Fraser LK, Ziegler L. A new scale assessing the stressors and rewards of children's hospice work. *BMC Palliat Care*. 2023 Sep 13;22(1):136. Bedendo A, Papworth A, Taylor J, Beresford B, Mukherjee S, Fraser L, Ziegler L. Staff well-being in UK children's hospices: a national survey. *BMJ Support Palliat Care*. 2023 Aug 29:spcare-2022-004056.





6. Paley CA, Johnson MI. Perspective on salutogenic approaches to persistent pain with a focus on mindfulness interventions. *Front Pain Res (Lausanne)*. 2023 Aug 29;4:1188758.
7. Burke S, Hopkins N, Divine A, Ebenso B, Allsop M. Physical activity service provision in hospice care: A national mixed-methods study. *Palliat Support Care*. 2023 Jun 27:1-9.
8. Clarke G, Crooks J, Bennett MI, Mirza Z, Obe RB, Nazar W, Mughal R, Ahmed S. Experiences of pain and pain management in advanced disease and serious illness for people from South Asian communities in Leeds and Bradford: a qualitative interview study. *BMC Palliat Care*. 2023 Jul 19;22(1):90.
9. Paley CA, Boland JW, Santarelli M, Murtagh FEM, Ziegler L, Chapman EJ. Non-pharmacological interventions to manage psychological distress in patients living with cancer: a systematic review. *BMC Palliat Care*. 2023 Jul 6;22(1):88.
10. Akoto EJ, Allsop MJ. Factors Influencing the Experience of Breast and Cervical Cancer Screening Among Women in Low- and Middle-Income Countries: A Systematic Review. *JCO Glob Oncol*. 2023 May;9:e2200359.
11. Paley EG, Johnson MI, Paley CA. Understanding pain in modern society: insights from attitudes to pain in the Medieval Period. *Front Pain Res (Lausanne)*. 2023 May 9;4:1162569. doi: 10.3389/fpain.2023.1162569.
12. EIMokhallalati Y, Chapman E, Relton SD, Bennett MI, Ziegler L. Characteristics of good home-based end-of-life care: analysis of 5-year data from a nationwide mortality follow-back survey in England. *Br J Gen Pract*. 2023 May 25;73(731):e443-e450. doi: 10.3399/BJGP.2022.0315.
13. Papworth A, Ziegler L, Beresford B, Mukherjee S, Fraser L, Fisher V, O'Neill M, Golder S, Bedendo A, Taylor J. Psychological well-being of hospice staff: systematic review. *BMJ Support Palliat Care*. 2023 Apr 25:spcare-2022-004012.

14. Akaba GO, Dirisu O, Yalma RM, Allsop M, Ebenso B. 2023. Innovative Application of Digital Health Solutions to Strengthen Health Systems and Improve Health Outcomes in Rural Populations of Abuja, Nigeria. *Topical Journal of Obstetrics and Gynaecology*. 39(3), pp. 383-397
15. Crooks J, Trotter S; Patient Public Involvement Consortium; Clarke G. How does ethnicity affect presence of advance care planning in care records for individuals with advanced disease? A mixed-methods systematic review. *BMC Palliat Care*. 2023 Apr 17;22(1):43.
16. Evaluating provision of psychological assessment and support in palliative care: A national survey of hospices in England. *Progress in Palliative Care* (accepted 16 Nov 23) E. Chapman, C. Paley, M. Farfan Arango, V. Keshwala, E. Hodgson, J. Birtwistle
17. Paley CA, Paley AT, Ziegler LE, Kane EC, McCleery I, Chapman EJ. Narrative review: what constitutes contemporary, high-quality end-of-life care and can lessons be learned from medieval history? *Ann Palliat Med*. 2024 Mar 7:apm-23-552. doi: 10.21037/apm-23-552. Epub ahead of print. PMID: 38462940.
18. Asuquo E, Absolom K, Ebenso B, Allsop M. 2024. Symptoms, concerns, and experiences of women living with and beyond breast cancer in Africa: A mixed-methods systematic review. *Psycho-Oncology: journal of the psychological, social and behavioral dimensions of cancer*.
19. Anik E, Hurlow A, Azizoddin D, West R, Muehlensiepen F, Clarke G, Mitchell S, Allsop M. Characterising trends in the initiation, timing, and completion of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process: Retrospective analysis of routine data from a large UK hospital trust. *Resuscitation*. 2024 Mar 7:110168. doi: 10.1016/j.resuscitation.2024.110168





20. Scanlon H, Latchford G, Allsop M. 'So being here is. . . I feel like I'm being a social worker again, at the hospice': Using interpretative phenomenological analysis to explore social workers' experiences of hospice work. *Palliat Med*. 2024 Mar;38(3):320-330
21. Onyeka TC, Emodi I, Mohammed AD, Ofakunrin AO, Alabi A, Onu JU, Iloanusi N, Ohaeri J, Anarado A, Umar MU, Olukiran G, Sowunmi A, Akinsete A, Adegboyega B, Chibuzo IN, Fatiregun O, Abdullah SU, Gambo MJ, Mohammad MA, Babandi F, Bok M, Asufi J, Ungut PK, Shehu M, Abdullahi S, Allsop M, Shambe I, Ugwu I, Ikenga S, Balagadde Kambugu J, Namisango E. In-hospital psychoeducation for family caregivers of Nigerian children with cancer (The RESCUE Study). *Palliat Support Care*. 2024 Mar 14:1-12
22. Wang Y, Allsop MJ, Epstein JB, Howell D, Rapoport BL, Schofield P, Van Seville Y, Thong MSY, Walraven I, Ryan Wolf J, van den Hurk CJG. Patient-reported symptom monitoring: using (big) data to improve supportive care at the macro-, meso-, and micro-levels. *Support Care Cancer*. 2024 Feb 22;32(3):182.
23. DeForge SM, Smith K, Anderson KA, Baltazar AR, Beck M, Enzinger AC, Tulskey JA, Allsop M, Edwards RR, Schreiber KL, Azizoddin DR. Pain coping, multidisciplinary care, and mHealth: Patients' views on managing advanced cancer pain. *Psychooncology*. 2024 Feb;33(2):e6308
24. Azizoddin DR, DeForge SM, Baltazar A, Edwards RR, Allsop M, Tulskey JA, Businelle MS, Schreiber KL, Enzinger AC. Development and pre-pilot testing of STAMP + CBT: an mHealth app combining pain cognitive behavioral therapy and opioid support for patients with advanced cancer and pain. *Support Care Cancer*. 2024 Jan 22;32(2):123
25. Robinson OC, Pini S, Flemming K, Campling N, Fallon M, Richards SH, Mayland CR, Boland E, Swinson D, Hurlow A, Hartup S, Mulvey MR. Exploration of pain assessment and management processes in oncology outpatient services with healthcare professionals: a qualitative study. *BMJ Open*. 2023 Dec 27;13(12):e078619. doi: 10.1136/bmjopen-2023-078619. PMID: 38151273; PMCID: PMC10753735.

26. Salako O, Enyi A, Miesfeldt S, Kabukye JK, Ngoma M, Namisango E, LeBaron V, Sisimayi C, Ebenso B, Lorenz KA, Wang Y, Ryan Wolf J, van den Hurk C, Allsop M. Remote Symptom Monitoring to Enhance the Delivery of Palliative Cancer Care in Low-Resource Settings: Emerging Approaches from Africa. *Int J Environ Res Public Health*. 2023 Dec 17;20(24):7190
27. Steinberg J, Hughes S, Hui H, Allsop MJ, Egger S, David M, Caruana M, Coxeter P, Carle C, Onyeka T, Rewais I, Monroy Iglesias MJ, Vives N, Wei F, Abila DB, Carreras G, Santero M, O'Dowd EL, Lui G, Tolani MA, Mullooly M, Lee SF, Landy R, Hanley SJB, Binefa G, McShane CM, Gizaw M, Selvamuthu P, Boukheris H, Nakaganda A, Ergin I, Moraes FY, Timilshina N, Kumar A, Vale DB, Molina-Barceló A, Force LM, Campbell DJ, Wang Y, Wan F, Baker AL, Singh R, Salam RA, Yuill S, Shah R, Lansdorp-Vogelaar I, Yusuf A, Aggarwal A, Murillo R, Torode JS, Kliever EV, Bray F, Chan KKW, Peacock S, Hanna TP, Ginsburg O, Van Hemelrijck M, Sullivan R, Roitberg F, Ilbawi AM, Soerjomataram I, Canfell K. Risk of COVID-19 death for people with a pre-existing cancer diagnosis prior to COVID-19-vaccination: A systematic review and meta-analysis. *Int J Cancer*. 2024 Apr 15;154(8):1394-1412. doi: 10.1002/ijc.34798. Epub 2023 Dec
28. Stevenson CJ, Harris-Joseph H, Harper L, Hewison J, Mulvey MR, Heuvelman H, McVicker C, Razalan MM, Knowles E, Ebanks B, Lee K, Fenton J, Thompson P, Cotterill LA. Experience of an NIHR Clinical Lectureship (medical/dental) and the determining factors for a clinical academic career post lectureship: a mixed-method evaluation. *BMJ Open*. 2023 Nov 17;13(11):e070536. doi: 10.1136/bmjopen-2022-070536. PMID: 37977870; PMCID: PMC10660434.
29. Paley CA, Keshwala V, Farfan Arango M, Hodgson E, Chapman EJ, Birtwistle J. Evaluating provision of psychological assessment and support in palliative care: A national survey of hospices in England. *Progress in Palliative Care*. 2024;32(1):11-21.
30. Abahussin AA, West RM, Wong DC, Ziegler LE, Allsop MJ. Supporting Pain Self-Management in Patients With Cancer: App Development Based on a Theoretical and Evidence-Driven Approach. *JMIR Cancer*. 2023 Oct 9;9:e49471. doi: 10.2196/49471. PMID: 37812491; PMCID: PMC10594136.
31. Langford L, Latchford G, Mulvey M. Can illness representations be used to understand pain experienced in breast cancer survivorship-a cross-sectional study. *J Cancer Surviv*. 2024 Jan 29. doi: 10.1007/s11764-024-01533-2.



32. Millares Martin P, Allsop MJ, Carder P. Will medical cause of death certifications data quality improve in the UK with the new medical examiner system? J Forensic Leg Med. 2023 Oct;99:102589. doi: 10.1016/j.jflm.2023.102589.

Papers submitted

1. A Framework for more equitable, diverse, and inclusive Patient and Public Involvement for palliative care research

Revised Submission to BMC Research Involvement and Engagement Sarah Mitchell¹ Nicola Turner² Kate Fryer³ Jude Beng (PPI co-author)³ Margaret E Ogden (PPI co-author)⁴ Melanie Watson⁵ Clare Gardiner⁵ Jo Bayly^{4,6} Katherine E Sleeman⁴ Catherine J Evans⁴

2. Integration of primary care and palliative care services to improve cultural competency and equity at the end-of-life: Findings from realist stakeholder workshops - Submitted to themed edition of Palliative Medicine Oct 2023. Mitchell S¹, Turner N², Fryer K³, Aunger J⁴, Beng J³ (PPIE), Couchman E⁵, Leach I³, Bayly J^{6,7}, Gardiner C⁵, Sleeman K⁴, Evans C⁴.

3. Reforming primary palliative care: a call to arms - Revised editorial for Br J General Practice, Couchman E, Richards S, Harlock J, Barclay S, Pocock L, Mitchell S

Conference poster:

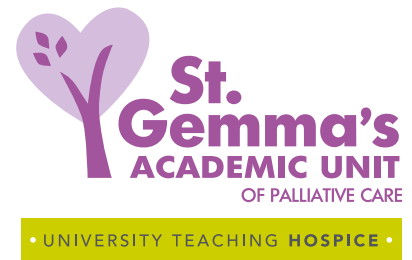
Vijayshankar, R. and Clarke, G. "48 Celebrating life: an innovative community engagement project with minoritized ethnic populations living in areas of socio-economic deprivation in North London: a service evaluation" The Marie Curie Research Conference 2024 Monday 5 February – Friday 9 February 2024. Challenging Inequity in Palliative and End of Life Care. BMJ SP Care, Volume 14 Supplement 1. January 2024.





St Gemma's Hospice
329 Harrogate Road
Moortown
Leeds, LS17 6QD

www.st-gemma.co.uk/AcademicUnit
0113 218 5500



in partnership with



UNIVERSITY OF LEEDS



Registered Charity No. 1015941