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**Awards at the Marie Curie Conference 2018**

Eight posters were presented at the Annual Marie Curie conference in London, October 2018.

Dr Emily Harrop was awarded the **Best Poster Award** for the systematic review category. Her poster related to the identification of Core Outcome Set (COS) for the evaluation of bereavement support services, “Interventions and support for people bereaved through advanced progressive illness: a mixed-methods systematic review”.

Professor Annmarie Nelson was awarded the **Best Primary-based Data Poster**. Her poster related to the PACT study, “Development of an intervention to support lung cancer patients and their clinicians when considering systematic anti-cancer therapy: the pact study, a prospective multicentre multi-methods five-stage qualitative study”.

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**Note from the Editor**

**Welcome** to the summer issue of the Marie Curie Palliative Care Research Centre (MCPCRC) newsletter for 2019.

This newsletter gives us an opportunity to share our latest news and events with you. With contributions from all our team members, here are some of our activities over the past few months.

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**Dr Anthony Byrne awarded an honorary chair by Cardiff University.**

“I look forward, for the tenure of the title, to supporting expansion of both the depth and reach of our Palliative and Supportive Care portfolio within the Cardiff University and the Wales Cancer Research Centre. In particular, I believe there is now even greater opportunity to strengthen the integration of academic and NHS research efforts, with closer alignment of strategies and pathways to clinical impact.”

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**Supporting our students**

We are pleased to announce that our MSc student, Miss Rachel Evans was awarded the Ilora Finlay award for receiving the joint highest mark (88%). An abstract from this thesis has been accepted for an oral presentation at the British Neuro-Oncology Society 2019 Annual Conference. Ms Evans was supervised by Dr Mirella Longo and Professor Annmarie Nelson.

For more information, please contact Dr Mirella Longo via longom1@cardiff.ac.uk

We supported a third-year medical student, Miss Isobel Woollons with the Self-Selected Component (SSC) project. Her project was to identify the feelings, wishes and experiences around end of life care with a qualitative approach. The data was collected from the death and dying survey data in Wales and the project was supervised by Dr Ishrat Islam.

For more information, please contact Dr Israt Islam via islam@cardiff.ac.uk
CURRENT PROJECTS

Rapid Review: Oxygen use - Perceptions of IPF patients and their carers.

Best supportive care and symptom palliation are mainstays of treatment for patients with Interstitial Pulmonary Fibrosis (IPF). As the disease advances, breathlessness becomes a major determinant of quality of life, yet anecdotal evidence suggests some patients are reluctant to instigate oxygen therapy. A rapid review has been conducted to understand key facilitators and barriers to the use of oxygen therapy from the perspective of patients with IPF and their carers.

Read the key findings here.

For more information, please contact Dr Amanda Woodward at woodwardaj@cardiff.ac.uk

EMPOWER: Evaluating a patient designed tool to reduce harm from Cancer Associated Thrombosis.

Cancer Associated Thrombosis (CAT) is a complication of cancer disease and treatment, resulting in the formation of a blood clot in the deep veins which may break off and embolise in the lungs. CAT affects up to 20% of patients during their cancer journey and is the commonest cause of cancer death, second only to cancer progression. Optimal CAT management has been shown to improve cancer survival, symptom burden and quality of life.

Recently, in partnership with patient groups Thrombosis UK and Anticoagulation Europe, a patient information video “Cancer, Chemo, and Clots” was produced. The video has been well received and nominated for a patient engagement award; however, it has yet to be formally evaluated.

The aims of this study are to explore whether the video “Cancer, Clots, and You” contribute to the patients’ ability to recognise symptoms, encourage patients to present to health professionals at an earlier rate and improve feelings of comfort and support in patient treatment journeys.

The EMPOWER Project seeks to analyse the efficacy of the video through looking at clinical data, patient experience, and nursing experience.

For more information, please contact Professor Simon Noble at nobles1@cardiff.ac.uk or Miss Elin Baddeley at baddeley1@cardiff.ac.uk
# CURRENT PROJECTS

## Scoping Review to support cReSt Cymru.

The cancer research strategy for Wales (CReSt Cymru) is a project of Wales Cancer Research Centre. The CReSt Cymru group feels there is a need to conduct a scoping review that aims to describe the current scenario of cancer research in Wales.

The scoping review will be conducted by producing three separate but interlinked documents. These documents will provide general information on some existing key strategy recommendations and barriers and enablers of cancer research throughout the UK as well as health professionals’ perceptions of barriers to and opportunities of cancer research in Wales.

For more information, please contact Dr Ishrat Islam via islam@cardiff.ac.uk

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## PhAB- Physical activity and Brain tumour.

Physical activity can have physical, psychological and social benefits on patients with brain-cancer, but engaging them in physical activity sessions might be challenging.

No studies have investigated what problems patients with advanced stage brain-cancer may face in taking part in physical activity or what may encourage them to become more active.

This study will find out what factors discourage and encourage patients with advanced stage brain-cancer to become more active in Wales and Bangladesh.

The study will compare the findings by considering the cultural and socio-economic differences between the participants in these two countries.

For more information, please contact Dr Ishrat Islam via islam@cardiff.ac.uk

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## Development of Guidelines for the communication of ReseArch results to patients, members of the public, and other StakeHOLder groups: The GIRASOL study

Dissemination of research results is now recognised as an integral part of the research process. It is no longer sufficient to communicate results solely through journal publication. Wider dissemination using a range of mechanisms, specifically targeting the lay community, enables the work to have impact outside of its academic base.

Most of the previous research has focused on the researcher’s perspective. This GIRASOL study will capture the views of other stakeholders, in particular the general public and participants in clinical trials and other health research studies. The aim of this study is to align the researcher’s perspective with other stakeholders’ views and preferences on how findings from health research should be made available to them.

The study is led by Mirella Longo, Annmarie Nelson and Julie Hepburn (our Research Partner) run by the MCPCRC, Cardiff.

**Three parallel surveys are currently being carried out. If you would like to help us by telling how health research studies should be made available, please follow the link that most reflects you:**

1. Are you a member of the general public who has NEVER participated before in a health research study (e.g. clinical trial)? please follow this link: [https://cardiff.onlinesurveys.ac.uk/girasol-survey_general-public](https://cardiff.onlinesurveys.ac.uk/girasol-survey_general-public)

2. Are you currently taking part or have in the past taken part in a health research study?, please follow this link: [https://cardiff.onlinesurveys.ac.uk/girasol-survey_health-study-participants-2](https://cardiff.onlinesurveys.ac.uk/girasol-survey_health-study-participants-2)

3. Are you a researcher who carry out health related research studies? Please follow the link below: [https://cardiff.onlinesurveys.ac.uk/girasol-survey_researchers](https://cardiff.onlinesurveys.ac.uk/girasol-survey_researchers)

For more information, please contact Dr Mirella Longo via longom1@cardiff.ac.uk
## Bereavement Outcomes Study

Palliative care has an established role in the provision of bereavement support. However, a lack of research and evidence-based guidance on bereavement support in palliative care has been noted. A limitation in the evidence-base has been a lack of consistency in the outcomes used to evaluate services and interventions, which makes it difficult to draw conclusions on their relative value and effectiveness. Core Outcome Sets (COS) represent the minimum that should be measured and reported in research or evaluations of a specific condition or service [www.comet-initiative.org](http://www.comet-initiative.org), making it easier for results to be compared, contrasted and combined. This project had two main objectives:

1. To systematically review the evidence on supportive interventions for people bereaved through advanced illness.
2. To develop a set of core outcomes that is specific to bereavement following advanced illness.

For more information, please contact Dr Emily Harrop via harrope@cardiff.ac.uk

## Weekend and bank holiday specialist palliative care service evaluation

The Cardiff and Vale University Health Board (CVUHB) weekend and bank holiday Specialist Palliative Care service was introduced in 2010. Delivered by Clinical Nurse Specialists, the service provides specialist advice and support with symptom control to people with non-curable illnesses and their families during weekends and bank holidays. In 2018, the MCPPRC was commissioned to review the service to inform its future sustainability and development. Soon to be published, the evaluation report draws together the results of a staff survey, interviews, and service performance data to outline aspects of the service that work well, the challenges and improvement opportunities.

For more information, please contact Ms Alisha Newman via newmana3@cardiff.ac.uk

## Evaluating the ‘Improving Access to End-Of-Life Care for Diverse Communities of Cardiff’ Project from service providers’ perspectives

Individuals with dementia, learning disabilities or those from specific spiritual backgrounds face challenges concerning accessing appropriate end-of-life care. The Marie Curie Hospice, Cardiff and the Vale, commissioned MCPPRC to conduct an evaluation on their ‘Improving access to end-of-life care for Diverse Communities of Cardiff’ project. The project was funded by the Big Lottery Fund, aiming to improve access to end-of-life care services for these specific diverse communities.

We designed an evaluation to externally determine the thoughts and views of Marie Curie Hospice staff and other organisations involved in the project; data was collected from survey responses and an interview with one individual from each of the three communities. The specific objectives of the evaluation of the were to:

1. Assess the impact the project has had on knowledge, awareness and confidence.
2. Assess the impact of the project concerning service quality and communication effectiveness.
3. Assess personal impact on service providers due to their involvement, specifically any future actions service providers intend to take forward.

We also conducted a rapid review into the barriers and facilitating factors for accessing and delivering palliative and hospice care facilities for people with dementia, learning disabilities and people from specific spiritual backgrounds.

For more information, please contact Dr Stephanie Sivell via sivells2@cardiff.ac.uk or Miss Elin Baddeley via baddeleye1@cardiff.ac.uk

## Recent Publications


- **Gaining an accurate reflection of the reality of palliative care through the use of free-text feedback in questionnaires: the AFTER study (2019) [https://spcare.bmj.com/content/9/1/e17](https://spcare.bmj.com/content/9/1/e17)
**NCRI, November 2018**

Dr Stephanie Sivell presented a poster on "Qualitative analysis of an innovative service for prostate cancer survivors with gastrointestinal radiotherapy late effects (the EAGLE study)" at the NCRI Cancer Conference in Glasgow, November 2018.

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**Hospice UK Conference, November 2018**

Professor Simon Noble, Dr Emily Harrop, and Dr Ishrat Islam delivered oral presentations at the Hospice UK conference. Dr Mirella Longo presented a poster at the conference.

Professor Simon Noble presented on "Reflexology in Palliative Care: Remove the placebo effect and what’s left?".

Dr Emily Harrop presented "Coping with grief: Identifying core outcomes for evaluating bereavement support in palliative care” at the Hospice UK Conference in Telford, November 2018.

**Top right:** Dr Mirella Longo presented "Recruitment of bereavement services users via hospices: reflections from the bereavement study” and Detailing public Involvement within a study of bereavement support services for adults bereaved through advanced illness".

**Above:** Dr Ishrat Islam presented on "End of Life Care and Decision Making: public knowledge, needs and preferences in Wales".

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**The Marie Curie Lecture Series, November 2018**

Professor Anthony Byrne conducted a panel discussion at the Marie Curie Lecture Series on “Making sense of end of life care: A good death in the age of ageing?” in Cardiff in November 2018.

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**WELCOME TO NEW STAFF/STUDENT**

**STAFF**

- **Alison Evans - Project Officer**
  Alison has joined the Marie Curie team as a Project Officer for the PaCERS team in November 2018. She mainly assists with conducting rapid reviews. She also works with the clinicians and other requestors of reviews and with students interested in learning the rapid review skill. She is also working with Dr Emily Harrop and Dr Cynthia Ochieng on the Bereavement Scoping Project in recruiting the survey respondents.

- **Dr Anna Torrens-Burton - Research Associate**
  Anna Torrens-Burton joined the Marie Curie team as a Research Associate in October 2018. Her job role primarily involves supporting projects on brain tumours under the guidance of Professor Anthony Byrne. She is currently working on a Cochrane systematic review examining the evidence for early palliative care interventions improving quality of life and survival in patients with malignant brain tumours. The review aims to provide a more thorough evidence base to help guide service provision for this patient population. She is also assisting the PACERS team with rapid reviews in a variety of topics and aiming to develop some work focusing on frailty markers in high grade glioma.

**STUDENTS**

- **Francesca Mazzaschi - PhD student**
  Francesca joined the Marie Curie team as a PhD student in October 2018 after completing her undergraduate degree in Biochemistry and a Master’s degree in Neuroimaging. Her PhD is focused on patients receiving radiotherapy for high grade glioma, with the goal of designing a screening tool for the detection of cognitive decline as a result of radiotherapy.

*For more information, please contact the newsletter team*

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