

# British Psychosocial Oncology Society 2023 Conference

Prevention, Early Detection and Diagnosis



Wednesday 22nd - Thursday 23rd March 2023  
Jesus College Cambridge

**BPOS**

**Understanding psychological harm on the cancer diagnostics pathway: what do services need to do better?**

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**Background:**

- Patients referred on a cancer pathway may experience psychological harm and distress whilst waiting for test results for diagnosis and treatment.
- Clinical harm is assessed regarding cancer waiting time breaches. Psychological harm is rarely assessed, if at all.
- In May 2021, a North Central London workshop identified psychological harm as an area to prioritise in cancer pathways.

Whilst the project is sponsored by NCL, engagement has taken place pan London.

**Aims**

1. Explore 'psychological harm' caused by waiting for diagnostics and first treatment
2. By understanding the impact of psychological harm, produce recommendations to improve patient care.

**Methods**

- A literature review was conducted regarding cancer and psychological harm and distress whilst waiting for tests. This did not include screening.
- Twelve semi-structured focus groups and interviews were held with patients, carers, psycho-oncologists, cancer nurses, cancer support workers, cancer GPs, practice nurses and a cancer surgeon. 36 people participated, and thematic analysis of transcripts was conducted.
- A stakeholder workshop was held in November 2022 which sought to understand the findings of the literature scan and focus groups, as well as identify pragmatic next steps to improve the diagnostic pathway for the psychological wellbeing of patients.

Results/conclusions: Assessing psychological harm is complex and not comparable to assessing clinical harm on a cancer diagnostics pathway. NHS services should be pro-active, personalised and prioritise minimising distress and promoting adjustment for both patient and family.

**Principles identified for service improvements included:**

- consistent, efficient and clear information & communication builds trust and reduces distress.
- providing named contact on receipt of referral
- from the start, explore emotional impact of referral, diagnostics and treatment process and potential obstacles to engagement.
- manage expectations about the pathway
- proactively identify needs and reasonable adjustments, at time of booking appointments
- involve family from the start & offer psychological interventions for families/significant others.



**Pilot lung screening in Scotland: intervention development and interim findings**

**Dr Debbie Cavers<sup>1</sup>**, Jasmin Rostron<sup>2</sup>, Dr Mia Nelson<sup>1</sup>, Mr Graeme Dickie<sup>1</sup>, Dr Christine Campbell<sup>1</sup>, Prof Katie Robb<sup>3</sup>, Prof Frank Sullivan<sup>4</sup>, Prof Edwin van Beek<sup>1</sup>, Dr Ahsan Akram<sup>1</sup>, Dr Melanie Mackean<sup>5</sup>, Prof Robert Steele<sup>6</sup>, Dr Lynsey Brown<sup>4</sup>, Prof David Weller<sup>1</sup>

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Objectives: We undertook a multi-method study to test the feasibility and acceptability of a lung screening intervention in Scotland, using low dose computed tomography. We aimed to understand people's views on, and barriers and facilitators to, lung screening, to test the process for lung screening in Scotland and obtain feedback on challenges in implementing screening. This paper will present the interim findings from the pilot study and some qualitative feedback on the process.

Methods: Patients for the pilot were identified via participating general practices using codes for smoking status. Those who responded were screened for eligibility using validated risk prediction tools. Patients assessed as high risk were offered a one-off low dose CT scan. Patients requiring any follow-up were referred to usual NHS care. A sub-group of participants and non-responders were interviewed to ascertain their views.

Results: To date, 153 patients have responded (approximately 22%) to a lung screening invitation. Eighty scans have been conducted for those at high risk. Further findings of participant characteristics and scan outcomes will be presented as well as a summary of findings from screening participant and non-responders interviews, noting views on and experiences of the lung screening process and challenges in the provision of lung screening at a local level, such as primary and secondary care burden and capacity issues, psychological barriers and the role of smoking cessation.

Conclusions: Implementation of lung screening must take into account the characteristics of the population it will serve and accommodate the barriers and facilitators to maximise uptake and improve outcomes. Our pilot study to explore the feasibility and acceptability of lung screening in the Scottish population is ongoing and has begun to explore implementation challenges to be addressed in any future lung screening programme, and identify how primary care can help optimise screening.

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### **Increasing awareness of gynaecological cancer and early detection in students: pilot study of a university-based educational and behaviour change intervention.**

**Dr Trish Holch**<sup>1</sup>, Prof Anne-Marie Bagnall<sup>2</sup>, Seren Hughes<sup>3</sup>, Kate Liston<sup>4</sup>, Lauren McSorley<sup>5</sup>  
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Background: Education is key to prevention, early detection and diagnosis of gynaecological cancer; however, many young people lack symptom knowledge. The key to detection is lifelong awareness, where women develop an understanding of the signs and symptoms to self-monitor and help seek effectively.

Aims: To assess baseline cancer awareness and explore the feasibility and acceptability of a university-based educational and behaviour-change intervention (a bespoke film from the charity Cancer Awareness in Teens and Twenties and an implementation intention exercise setting tangible goals to self-monitor and help-seeking) in a large UK University. The findings will be used to develop a multi-centre-trial with potential for national rollout.

Methods: Sixty-three participants (30 intervention; 33 control) 81% white British, all identifying as women aged (M=21:31, SD=5.8) participated in an online randomised, repeated measures mixed methods feasibility study. Completing the Young Person Cancer Awareness Measure (YPCAM) and Theory of Planned Behaviour (TPB) questionnaires at baseline, 4 weeks, 3 and 6 months. Interviews were conducted with intervention group participants (n=6), thematic analysis was employed.

Results: Recruitment at baseline was successful, missing data was low, (0.3% YPCAM; 0.01% TPB). Seventy four percent of the overall sample (N=63) overestimated their cancer risk but were only able to identify (M= 3.0, SD = 1.7) number of symptoms correctly. Forty three percent would seek medical help within a week for an unexplained lump and bleeding after sex. The film was well received, informative “how did I not know about this?” and valuable “It’s such an important video...I think it should be everywhere”; In terms of behaviour change, participants reported more confidence in advocating for themselves from completing the intervention.

Conclusions: Recruitment was successful and the intervention acceptable and valuable to participants. Ultimately, the intervention will empower young people to be aware of and seek help for symptoms of gynaecological cancer.

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### **“I was just an open book and they were writing the pages...” A qualitative exploration of the impact of health literacy on the route to diagnosis in head and neck cancer (HNC) patients.**

**Jennifer Deane**<sup>1</sup>, Dr Christina Dobson<sup>1</sup>, Prof Gill Rowlands<sup>1</sup>, Prof Joanne Patterson<sup>2</sup>, Dr Fiona Menger<sup>1</sup>, James O’Hara<sup>1,2</sup>, Michael Nugent<sup>4</sup>, Val Bryant<sup>5</sup>, Jennifer Dunbar<sup>5</sup>, Suzanne Miller<sup>5</sup>, R. Barry Phillips<sup>5</sup>, Prof Linda Sharp<sup>1</sup>  
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Background:

In the UK, more than 6 in 10 HNCs are diagnosed at a late stage. Stage is a significant prognostic factor: 5-year survival for stage 1 oral cancer disease is approximately 80% vs 20% for advanced disease. The reason for the high frequency of late stage disease is believed to be delays in diagnosis.

Health literacy is the ability to access, understand and appraise information and services in relation to health. Suboptimal health literacy is more prevalent amongst groups within society at greater risk of HNC. Therefore it is possible that low health literacy could play a role in delay to HNC diagnosis.

Aims: To explore the role of health literacy in patients' accounts of their route to HNC diagnosis.

Methods: Secondary analysis of qualitative interviews conducted within two previous projects with HNC patients. Thematic analysis, informed by a health literacy framework was undertaken. 39 patients were included in the analysis (23 Male/16 Female). To aid interpretation, the results were mapped onto the Anderson Model of Total Patient Delay.

Results/Conclusions: Analysis indicated that there were 4 themes; Knowledge which underpinned 3 overlapping themes: Relationships, Negotiation of the Healthcare System and Push and Pull. Knowledge covered knowledge of cancer and the healthcare system. Relationships encompassed the impact of relationships with healthcare professionals (HCP), importance of trust, ability to challenge and take control. Negotiation of the Healthcare System considered how help was sought, how information was managed and communication. Push and Pull referred to the barriers and facilitators to entering the healthcare system and the impact of community knowledge.

The role of health literacy is evident in the appraisal and help-seeking intervals of the Anderson Model. Interventions to improve health literacy, and/or modify health services to better accommodate people with suboptimal health literacy, are needed to reduce cancer diagnostic delays.

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**Wednesday 22nd March**  
**Oral Session 2: Cancer pathways**

**An update on the London Integrated Pathway for Cancer Psychosocial Support: what impact has it made in London and across the UK?**

**Dr Philippa Hyman<sup>1</sup>, Ms Yvonne Beadle**

*<sup>1</sup>Transforming Cancer Services Team for London (NHS), London, England, <sup>2</sup>Macmillan Cancer Support, London, England*

Background:

- For many years in London there was recognition that the psychosocial needs of those affected by cancer were not being adequately met with confusion regarding when, how and where to refer.
- Between 2017 and 2020 Macmillan Cancer Support funded and worked in partnership with the Transforming Cancer Services Team (TCST) in London to develop an integrated pathway to deliver excellent psychosocial support from diagnosis, through treatment, living with and beyond cancer and end of life care.
- Since the development of the London Integrated pathway for cancer psychosocial support, there are several examples of how this model has been adopted within London and Nationally.

Aims: To understand over the last eighteen months, at a regional and National level how 'The London model' has been adopted and adapted within cancer systems and been used strategically.

Methods: Engagement with key stakeholders within London and Nationally to understand how the pathway has been used across cancer systems and strategically.

Results/Conclusions:

- Macmillan Cancer Support have prioritised the roll out and evaluation of the 'London model' across the 4 nations of the UK with significant financial investment.
- Improving cancer psychosocial support is now an NHS England priority forming part of the planning guidance for cancer alliances for 2022/23 onwards.
- The pathway and suite of documents published by TCST have been used across multiple geographies to identify gaps in services and as the basis for developing successful business cases. Many psycho-oncology services have been established as a result.
- Further evaluation is needed to understand the impact of these developments 'on the ground' from the referrers and patient perspectives. Additionally, further evaluation of system and economic impact would also be beneficial. Both are planned as part of Macmillan Cancer Support's development, investment and evaluation programme.

## **The Psychosocial Cancer Evaluation Toolkit: developing a tailored evaluation protocol and interface for the evaluation of cancer support initiatives**

**Zoe Cooke**<sup>1</sup>

<sup>1</sup>*University of Wales Trinity Saint David, Swansea, Wales, UK*

**Background:** Within the UK alone there exists a plethora of psychosocial interventions and initiatives that seek to support those affected by cancer through a variety of mechanisms. Whilst clinical care and treatment of cancer are delivered within the UK National Health Service (NHS), a significant amount of psychosocial care is delivered through third-sector organisations in the form of cancer charities. In general these services can suffer from a lack of robust and comparable evaluation which prevents them from evidencing the impact they may have on psychosocial outcomes. This research was conducted as part of a KESS2 funded PhD studentship in partnership with Tenovus Cancer Care.

**Aims:** To develop a psychosocial evaluation toolkit and bespoke user-friendly computer interface to evaluate the psychosocial impact of cancer support services provided by Tenovus Cancer Care.

**Methods:** A mixed methods and mixed discipline design incorporating a systematic review of cancer PROMS, an E-Delphi to explore consensus on the most important and relevant psychosocial health outcomes, user experience evaluation (UX) of the data visualisation interface and a pilot psychological evaluation to assess the feasibility and acceptability of the Tenovus: Psychosocial Outcomes Toolkit (T:POT) interface.

**Results/Conclusions:** A set of four PROMS (FACT-G, SF-SUNS, CLS, FCR) measuring quality of life, unmet needs, cancer loneliness and fear of recurrence were selected to form the basis of the T:POT based on the outcome of the systematic review and e-Delphi study. The T:POT interface worked well and most UX elements such as ease of use, design, and reliability, were considered above average against the benchmark standards. The final evaluation revealed the T:POT achieved the desired outcome and was fit for purpose. It revealed that development and a larger scale evaluation was needed to test its full functionality and ability to directly compare services and evidence impact.



## **Integrating Psychology within a Rapid Diagnostic Cancer Clinic - Early Findings & Future Directions**

**Dr Sahil Suleman**<sup>1,2</sup>, Mrs Tracey Preston<sup>1</sup>, Dr Owen Carter<sup>1,3,4</sup>, Dr Anna-Mary Young<sup>1</sup>

<sup>1</sup>*St George's University Hospitals NHS Foundation Trust, London, UK*, <sup>2</sup>*University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK*, <sup>3</sup>*Lavender Hill Group Practice, London, UK*, <sup>4</sup>*RM Partners – West London Cancer Alliance, London, UK*

**Background:** Whilst psycho-oncology is more well-established as a core part of cancer care following a diagnosis, the role of psychology early in the diagnostic end of the pathway is more nascent in its development.

As part of Long Term Plan (LTP) ambitions for faster diagnosis of cancer, Rapid Diagnostic Centres (RDC) are being rolled out nationally to develop pathways for patients with non-specific/concerning physical symptoms to exclude/make a cancer diagnosis.

Whilst many RDCs have input from multiple specialties, the St George's RDC in SW London is the first in the country to embed psychology as part of the holistic multidisciplinary clinic, in response to a local pilot identifying the potential value for integrated psychology.

**Methods:** Our presentation seeks to share the rationale that drove our service development and provide an insight into considerations and challenges for psychology working early in the pathway and how this impacted service design. Qualitative and quantitative data spanning the 87 patients referred for psychology input and multidisciplinary colleagues will be shared to demonstrate clinical impact.

**Results:** The data highlights common profiles of patients under the RDC requiring psychology input and the role of rapid assessment and short-term psychological intervention in facilitating access to diagnostics. The importance of pre-existing psychological vulnerabilities and new onset heightened distress associated with the diagnostic processes will be highlighted, along with the need to work closely with all aspects of the diagnostic pathway system and primary care. Results will also highlight the importance of a stepped care approach, keeping pathways responsive and training/supervision.

**Conclusions:** Key learning and future directions for the psychology component of the RDC will be shared, particularly as the service has now been substantively funded. Challenges with more rigorous evaluation will also be discussed along with proposed next steps in this exciting new field for psycho-oncology.



## Optimising the care and support of people with inoperable pancreatic cancer - healthcare professional perspectives

**Hilary Brown<sup>1</sup>**, Dr Lucy McGeagh<sup>1</sup>, Prof Eila Watson<sup>1</sup>, Prof Annie Topping<sup>2</sup>

<sup>1</sup>Oxford Brookes University, Oxford, UK, <sup>2</sup>University of Birmingham, Birmingham, UK

Pancreatic cancer is the tenth most common cancer in the UK but the 5th highest cause of mortality, with five-year survival just over 7%. One in 4 people will die within one month of diagnosis and 3 in 4 people will die within a year of diagnosis. Surgery is the only curative treatment but less than 10% of patients are suitable for surgery.

This research aims to explore health care professional (HCP) experiences of providing care and support to people with inoperable pancreatic cancer and their family carers. The research examines the challenges in providing timely and effective supportive care for a complex cohort of patients with multiple and often intractable needs.

This is a qualitative study involving sixteen healthcare professionals drawn from two geographic areas, incorporating NHS acute and community-based staff, and from the UK's specialist pancreatic cancer charity – Pancreatic Cancer UK. Semi-structured interviews were conducted by phone or Zoom between May and November 2022. The interview data were analysed using the Framework Analysis Approach.

Interviewees spoke of their desire to have more proactive and longer interactions with patients. However, capacity constraints often require an unsatisfactory 'call us when you need us' approach. Studies note that caring for people with cancer can cause significant work-related stress, dissatisfaction, and exhaustion which in turn may lead to the phenomenon known as 'moral injury' - defined as the psychological distress which results from actions, or the lack of them, which violate an individual's moral or ethical code. It is probable that some HCPs may already be experiencing moral injury, while others may be at risk of developing it. HCPs therefore need access to effective psychological support to avoid burnout and to enable them to cope with their role, particularly in the context of a cohort of patients with a distressing prognosis.

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### Thursday 23rd March

#### Oral session 3: Route to diagnosis - underserved communities

#### Symptom appraisal and help-seeking prior to receiving a cancer diagnosis during or shortly after pregnancy: A qualitative interview study

**Dr Afrodita Marcu<sup>1</sup>**, Dr Jenny Harris<sup>1</sup>, Dr Karen Poole<sup>2</sup>, Dr Lisa Whittaker<sup>3</sup>, Prof Faith Gibson<sup>1</sup>, Prof Emma Ream<sup>1</sup>, Prof Jo Armes<sup>1</sup>

<sup>1</sup>University of Surrey, Guildford, UK, <sup>2</sup>The Institute of Cancer Research, Sutton, UK, <sup>3</sup>King's College London, London, UK

Background: Diagnosing cancer in pregnancy can be difficult because the physical changes occurring in pregnancy can mask the symptoms of cancer, potentially leading to misattribution of symptoms and delays in diagnosis and treatment.

Aims: To explore women's symptom appraisal and help-seeking prior to being diagnosed with cancer during pregnancy.

Methods: Qualitative semi-structured interviews conducted over Zoom with 20 women recruited via the charity Mummy's Star (age range 27 to 45 years), diagnosed with cancer whilst pregnant (n=17) or shortly after giving birth (n=3). Thirteen participants had been diagnosed with breast cancer and 7 participants with bowel cancer, Hodgkin and non-Hodgkin lymphoma, thyroid cancer and melanoma, respectively. The data were analysed using reflexive thematic analysis and the themes were mapped onto the Model of Pathways to Treatment.

Results: Three prominent themes will be the focus of the presentation. "Interpreting the symptoms through the lens of pregnancy" indicates that many participants and healthcare professionals made sense of symptoms in light of their expectations around bodily changes during pregnancy, which in some cases led to delay in the cancer diagnosis. "Attributing initial symptoms to other health conditions or causes" shows that participants' initial symptoms were often attributed to other conditions, either by the themselves or by healthcare professionals. "Subjective appraisal of the timeliness of diagnosis" shows how the participants felt about their journey to a cancer diagnosis, with some wishing they had been diagnosed sooner, and others feeling ambivalent about an earlier diagnosis, as this would have marred their enjoyment of pregnancy or may have led to difficult choices around continuation of pregnancy.

Conclusions: This study details women's symptom interpretation and help-seeking for symptoms indicative of cancer during pregnancy. It also offers insight into how the timeliness of the cancer diagnosis is perceived in the context of pregnancy.

## **Understanding seldom heard voices: Black African, Caribbean, Black British and Mixed-Black women's views and experiences of uterine cancer in the UK to inform strategies to promote early presentation of symptoms**

**Dr Nessa Millet<sup>1</sup>**, Dr Natalie Darko<sup>1</sup>, Dr Rebecca Barnes<sup>1</sup>, Dr Esther Moss<sup>1,2</sup>

<sup>1</sup>*The University of Leicester, Leicester, UK*, <sup>2</sup>*University Hospitals of Leicester NHS Trust, Leicester, UK*

**Background:** Research, mainly conducted in the United States, reports that mortality rates from uterine cancer are significantly higher in Black women as compared to patients from other ethnic groups. Detection at an early stage through symptom presentation has been proposed as a factor contributing to this disparity. Little is known about how uterine cancer is viewed and experienced within Black ethnic communities in the UK. This study aimed to understand the views and experiences of Black ethnicity women resident in the UK regarding uterine cancer, with a focus on understanding how early presentation of symptoms could be best promoted.

**Methodology:** Eighteen Women of Black African, Caribbean, Black British and Mixed-Black ethnicity were purposefully recruited. Focus groups and interviews were conducted to understand knowledge of symptoms; attitudes towards uterine cancer; and views on promoting symptom awareness and early presentation within Black ethnic communities. Inductive thematic analysis was used to analyse the interview data.

**Results:** The results suggest that there is stigma related to discussing gynaecological health within Black ethnic communities, which negatively impacts discussion of symptoms, such as irregular vaginal bleeding. Cultural models of illness (e.g., only accessing healthcare in extreme cases) and norms including gender roles (e.g., prioritising familial well-being over one's health) also appear to interfere with the consumption of health information. A lack of specific knowledge mobilisation and targeted uterine cancer information appears to contribute to the normalisation of red flag symptoms and a narrative of cancer fear. It was felt that information provision should be language and setting appropriate and should be disseminated from a trusted source to enhance accessibility.

**Conclusions:** The insights and information obtained from this study will guide the development of culturally-sensitive information provision and clinical services aimed at reducing health inequalities and improving uterine cancer prognosis in Black ethnicity women in the UK.



## **Barriers and facilitators to cancer screening for people with chronic illnesses or disabilities: A systematic review of qualitative research**

**Rebecca Spencer<sup>1</sup>**, Prof Georgina Jones<sup>1</sup>, Prof Ramzi Ajjan<sup>2</sup>, Dr Rebecca Birch<sup>2</sup>, Oluwanilo Awoloto<sup>2</sup>, Dr Laura Ashley<sup>1</sup>

<sup>1</sup>*Leeds Beckett University, Leeds, UK*, <sup>2</sup>*University of Leeds, Leeds, UK*

**Background:** Individuals with chronic illnesses and disabilities are less likely to participate in cancer screening than people without, with some research indicating that cancer screening participation rates decline as levels of morbidity or disability increase.

**Aims:** This systematic review aimed to: (1) better understand the illness and disability-related barriers and facilitators to cancer screening participation experienced by people with chronic illnesses and disabilities; (2) understand how clinical and sociodemographic characteristics influence these barriers/facilitators; and (3) identify limitations and gaps in this literature to date.

**Methods:** CINAHL, Medline and PsycInfo were searched, using a search strategy developed based on the Adult Co-Morbidity Evaluation-27. Citation searching (backward and forward) was conducted. Studies containing qualitative data about experiences of/perspectives on cancer screening, from people with one or more chronic illnesses (physical or mental) and/or disabilities (physical or intellectual) were included. All screening (title, abstract and full-text) was 100% conducted by two independent reviewers. 20% of data extraction and quality appraisal (using the Mixed Methods Appraisal Tool) was double-checked. Thematic synthesis was conducted, with 10% of articles double-coded.

**Results/Conclusions:** Seventy articles were included, covering a range of chronic illnesses and disabilities. Most studies focussed on cervical and/or breast cancer screening. Having a chronic illness or disability exacerbated existing barriers to screening (e.g. pain/discomfort; anxiety) and added additional barriers. Individuals frequently experienced reduced physical and/or psychological capability to participate, which was often compounded by having additional work to perform (e.g. arranging medical transport; self-advocating). Barriers beyond the individual's control (e.g. inaccessible screening facilities), sometimes proved insurmountable. Occasionally, individuals were advised against screening, due to increased risks and/or reduced benefits. This is the first systematic review to synthesise qualitative evidence about cancer screening, from people with any type of chronic illness or disability. The findings will identify areas for further research and may inform future interventions.



## **Custody or care: being diagnosed and treated for cancer in prison**

**Prof Jo Armes<sup>1</sup>**, Dr Renske Visser<sup>1</sup>, Dr Philip Mullen<sup>1</sup>, Dr Rachel Taylor<sup>1</sup>, Dr Emma Plugge<sup>1</sup>, Jennie Huynh<sup>1</sup>, Dr Margreet Luchtenborg<sup>1</sup>, Prof Rachel Hunter<sup>1</sup>, Dr Elizabeth Davies<sup>1</sup>  
<sup>1</sup>*University of Surrey, Guildford, UK*

**Introduction:** People in prison often have multiple, complicated health problems, yet little is known about the burden of cancer in this group. We conducted a sequential explanatory mixed methods study to assess the incidence and cost of cancer in English prisons and explored experiences of providing/receiving cancer care.

**Methods:** The qualitative interview study explored experience of diagnosis and treatment from patients (n=24), oncology clinicians (n=9) and prison staff (n=22) perspectives. Interviews were audio-recorded and data were analysed thematically.

**Results:** Interviews revealed cancer care in prison is complex. Three central organising concepts were identified: control and choice, communication, and care and custody. By mapping our findings to the cancer pathway we identified that people in prison follow a similar diagnostic pathway compared to those in the community. However, there are several barriers to diagnosis including health literacy, the process for booking a GP appointment and communication both between prison staff and oncology clinicians. Not all barriers were specific to people in prison, some are experienced by people residing in the community but many are exacerbated by the prison environment. Prisons limit control and choice, yet hospitals aim to be inclusive and empowering. We found tensions between control and choice in prison impact peoples' experiences of symptom management, accessing cancer information, and family involvement in their care.

**Conclusions:** This is the first qualitative study to explore cancer care in prison from the experience of both patients and professionals. Our findings demonstrate the complexity of cancer care in custodial settings and identifies barriers and enablers to equitable cancer care provision and offers insights as to how cancer care for this population potentially could be improved.

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**Thursday 23rd March**  
**Oral session 4: Children, Teenagers and Young Adults**

### **A qualitative investigation into the psychosocial needs of teenagers and young adults who have had Retinoblastoma**

**Mrs Nicola O'Donnell<sup>1</sup>**, Dr Bob Phillips<sup>1</sup>, Dr Jess Morgan<sup>1</sup>, Dr Debra Howell<sup>1</sup>  
<sup>1</sup>*University of York, York, UK*

Retinoblastoma (Rb) is a rare cancer of the retina that is diagnosed in ~50 children in the UK annually, with 45% of cases due to hereditary factors. Despite being highly curable, Rb can have huge impact on the wellbeing of individuals long after remission. Existing research highlighted the need for psychosocial support in this population, however the nature of this is under-researched and largely unavailable.

A qualitative study was conducted: focus groups with 16 teenagers (13-19 years) and individual interviews with 16 young adults (20-29 years) (TYA) with a history of Rb. The study aimed to explore living beyond Rb and challenges that may be faced as a result. A narrative approach explored life-stories of individuals and aimed to gain clear understanding of transition to adulthood. It also sought views on challenges experienced and current psychosocial support they access or felt could be beneficial.

Data was collected between June 2022 – January 2023 and analysed using reflexive thematic analysis. TYA discussed increased anxiety, both socially and in terms of their health. This included concerns about second cancers, and about passing on Rb genes to future children. For many, they internalised Rb and the domination of this on their identity. There was also a focus on a lack of targeted psychological support, and the need for education amongst others about the long-term impact of childhood cancer.

TYA who have had Rb appear to be at increased risk of anxiety and identity-related distress. This is particularly apparent for those with the hereditary variant, as well as those who were treated with enucleation and therefore have a visible difference that others can detect. There is also a high need for targeted Rb psychosocial support, which is supported by existing evidence and supports our plan to develop a novel psychoeducation intervention for this population.

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## **'I probably should take that more seriously': A young adult perspective of cancer risk, early prevention and detection**

**Lucy King<sup>1</sup>**, Dr Nova Deighton-Smith<sup>1</sup>, Dr Patricia Holch<sup>1</sup>

<sup>1</sup>Leeds Beckett University, School of Humanities and Social Sciences, Leeds, UK

Background: Young people aged 16-30 in the UK are faced with a plethora of cancer information and guidance that rarely resonates with them or meets their health needs. This lack of representation and awareness risks creating a false sense of security and reduced engagement, thus impacting whether symptoms are recognised and responded to. Health research has illustrated gender differences in cancer awareness and health seeking attitudes, prompting questions surrounding who may be most at risk of missed diagnosis and early prevention and detection opportunities.

Aims: To explore cancer awareness, preventative and help-seeking behaviours in young people via interview and consider the barriers and facilitators to these actions, with particular attention on gender roles.

Method: Twenty-one participants (7 men, 14 women) aged 16-30 were recruited using online platforms. Seventeen took part in qualitative, semi-structured recorded interviews via telephone or videocall, and one focus group (n=4) took place. Verbatim interview transcripts were analysed using a hybrid inductive and deductive reflexive thematic analysis.

Results/conclusions: In terms of cancer prevention and help-seeking, participants expressed feeling in a 'safe zone', beyond childhood risks but too young to fear adult cancer, and expressed fear of taking resources away from perceived 'more worthy' others. There was a strong expression that women's health encompassed cancer in a way that men's health did not, in part to due societal attitudes, and medicalisation of women's bodies from an early age. Body-image also impacted prevention both in private and help-seeking scenarios. Social relationships impacted help-seeking, with a strong importance placed upon behaviour of comparable peers. Close experience of cancer provided motivation for action.

These study findings have informed the development of a mixed-method nationwide survey (currently underway) to explore a more diverse population, and to provide insight into avenues for empowerment to equip young people in cancer prevention and help-seeking.



## **Young adult cancer patients' experiences of diagnosis and treatment during COVID-19**

Rachel Sauvarin<sup>1</sup>, **Dr Emily Arden-Close<sup>1</sup>**

<sup>1</sup>Bournemouth University, Poole, UK

Background: COVID-19 was declared a pandemic on 11th March 2020, leading to lockdowns around the world and disruptions in healthcare, including changes to cancer treatment. Cancers, particularly blood cancers such as lymphoma, common in young adults, are associated with risk of a weakened immune system, and chemotherapy increases the risk of patients becoming seriously ill should they develop COVID-19. Many cancer patients were advised to shield during the COVID-19 pandemic, both from the outside world and within their homes, which had the potential to lead to poor psychosocial wellbeing due to isolation and anxiety. This was particularly likely to impact young adults, who tend to have a broader social circle than older people.

Aims: To explore the impact of cancer diagnosis and treatment during the COVID-19 pandemic on young adult cancer patients (aged 18-32 years) in the UK.

Methods: Semi-structured audio interviews were conducted online via Zoom with 20 participants (mean age 24.5 years; 75% female; 20% male, 5% nonbinary), recruited via an online support group for young people with cancer. Inclusion criteria were age 18-32 and receiving cancer treatment in the UK during the COVID-19 pandemic. Data was audio recorded, transcribed verbatim and analysed using thematic analysis.

Results/Conclusions: In addition to the emotional impact of the diagnosis and physical and mental health impacts of treatment, further pandemic-related impacts included feelings of vulnerability, lack of access to services, modifications in treatment procedures and negative impacts of shielding. Facilitators to coping included social support, keeping occupied, exercising, access to Teenage and Young Adult (TYAC) cancer services, positive adaptations to COVID-19, and ability to access online services. Barriers included some COVID-19 adaptations to healthcare and lack of support. Regional disparities were identified. Future research should investigate longer-term impacts of the pandemic on young adult cancer patients, now most are vaccinated against COVID-19.



## Barriers and facilitators to self-management in people living with a low-grade glioma

**Mr Ben Rimmer<sup>1</sup>**, Miss Michelle Balla<sup>1</sup>, Dr Lizzie Dutton<sup>1</sup>, Dr Sophie Williams<sup>2</sup>, Prof Vera Araújo-Soares<sup>3</sup>, Prof Pamela Gallagher<sup>4</sup>, Prof Tracy Finch<sup>5</sup>, Dr Joanne Lewis<sup>2</sup>, Dr Richéal Burns<sup>6</sup>, Dr Fiona Menger<sup>1</sup>, Prof Linda Sharp<sup>1</sup>  
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**Background:** In cancer, as well as other chronic conditions, self-management can have clinical, psychosocial, and health economic benefits. However, many factors might influence patients' engagement in self-management. Low-grade glioma (LGG) patients are rarely cured and may face chronic, tumour-specific symptoms and impairments (e.g. cognitive deficits, seizures), which could distinctively influence their ability to self-manage.

**Aims:** Our study aimed to identify and explore the barriers and facilitators to self-management in LGG patients.

**Methods:** We conducted semi-structured interviews with a diverse group of 28 LGG patients, recruited from across the UK, who had completed primary treatment. Sixteen participants were male, mean age was 50.4 years, and mean time since diagnosis was 8.7 years. Interviews were audio-recorded and transcribed. Following inductive open coding, findings were deductively mapped to the self-management framework of Schulman-Green et al., which encompasses factors influencing self-management, developed in chronic illness.

**Results/Conclusions:** We found supporting evidence for five categories within the framework, encompassing 18 factors influencing self-management, namely: 'Personal/lifestyle characteristics' (factors: Knowledge, Beliefs, Psychological distress, Motivation, Life transitions), 'Health status' (Co-morbidity, Illness severity, Symptoms/side-effects, Cognitive functioning), 'Resources' (Financial, Equipment, Psychosocial), 'Environmental characteristics' (Home, Work, Community), and 'Healthcare system' (Access, Navigating system/continuity of care, Relationship with provider). Most factors were on a continuum, for example, sufficient financial resources was a facilitator of self-management, whereas a lack thereof, was a barrier. There was evidence of interactions between factors (e.g. Motivation and Navigating system; Community environment and Psychosocial resources).

This is the first study to investigate the barriers and facilitators to self-management in LGG patients, highlighting the distinctive experiences and wide-ranging factors influencing self-management in this patient group. These findings are being used to inform the design of a supported self-management intervention for LGG patients.



## Challenges of managing diabetes during cancer treatments: a qualitative interview study with patients and clinicians in the UK

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**Background:** Cancer treatment can adversely impact diabetes management and control, and there is accumulating evidence that suboptimal glycaemic control during cancer treatment is a contributory driver of worse cancer-related outcomes in patients with comorbid diabetes.

**Aims:** To understand patients' and clinicians' challenges and support needs around managing diabetes during cancer treatments, and identify potential ways to address these.

**Methods:** Semi-structured individual interviews with 27 people with diabetes (type 1 or type 2) undergoing anti-cancer treatment and 40 clinicians involved in caring for this patient group (e.g., oncologists, diabetologists, specialist nurses, general practitioners). Data were collected 2021-22 and analysed using framework analysis. Data collection and analysis were informed by the Theoretical Domains Framework.

Results / Conclusions: Themes were developed for the patient data (5 themes, 12 subthemes) and clinician data (5 themes, 12 subthemes), to capture challenges around managing diabetes during cancer treatments. Patient-experienced challenges included: reliance on preexisting diabetes toolkits and care provision; being underinformed and unsure about cancer clinicians' involvement in monitoring and caring for their diabetes; and a heavy onus on patients to self-manage and seek-out information and support for this dual-condition issue. Clinician-experienced challenges included: perceived wider but unspecified goalposts for diabetes control in this cancer context; wariness of overburdening patients; and insufficient capacities to assume primary professional responsibility for this dual-condition issue, plus little interprofessional collaborative working. During anti-cancer treatments clinical practice and systems somewhat place diabetes control 'on the backburner', providing mainly reactive care 'when it boils over', rather than seeking to pre-optimize patients' diabetes care and control.

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## **ROC-oN: Radiotherapy for Oropharyngeal Cancer and impact on Neurocognition**

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Background: Oropharyngeal cancer (OPC) is a type of head and neck cancer that develops in the oropharynx. Patients treated with radiotherapy for OPC receive a low dose of radiotherapy to the base of the brain. This could lead to late-effects including fatigue and neurocognitive deficits. Until now, existing data are sparse, heterogeneous, and involve low numbers.

Aim: To evaluate long-term fatigue and neurocognitive impairment in patients who have received radiotherapy for OPC.

Methods: This study uses a cross-sectional, mixed-methods design. Patients are being recruited from Leeds Teaching Hospitals NHS Trust and The Christie NHS Foundation Trust. Eligibility criteria: adult OPC patients, irradiated over the previous 10 years, ≥ 2 years after treatment, and who remain disease free. Participants are being invited by post to complete a survey consisting of several validated questionnaires regarding fatigue (Multidimensional Fatigue Inventory), neurocognition (Medical Outcome Studies Cognitive Function Scale), health-related quality of life (EQ-5D-5L), mood (Profile of Mood States short form) and work (Work Productivity Activity Impairment). Participants are also invited to complete the Amsterdam Cognition Scan (ACS) online to measure neurocognition. A sample of participants will partake in semi-structured qualitative interviews.

Results: Data collection has started in Leeds and will start at The Christie in February 2023. To date, there have been 65 (out of 357) surveys returned. Until now, 24 participants have also completed the ACS. Leeds participants will be sent a reminder in mid-January. Interviews with a sub-sample of survey participants have begun. By March 2023 we will be able to present emerging mixed-method findings.

Conclusions: Quantifying the magnitude of late-effects, including long-term fatigue and neurocognitive impairment in patients previously irradiated for OPC will raise awareness of these treatment-related side effects. This allows future efforts to be made to appropriately consent patients for these side effects and manage and/or mitigate these problems.

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## **Impact of Pre-existing Mental Health Disorders on The Receipt of Guideline Recommended Cancer Treatments: A Systematic Review**

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Background: Disparities in cancer outcomes for individuals with pre-existing mental health disorders have already been identified, particularly for cancer screening and mortality.

Aims: We aimed to systematically review the influence on the time from cancer diagnosis to cancer treatment, treatment adherence, and differences in receipt of guideline recommended cancer treatment.

Methods: We included international studies published in English from 1 January 1995 to 23 May 2022 by searching MEDLINE, Embase, and APA PsycInfo.

Results: This review identified 29 studies with 27 being published in the past decade. Most studies focused on breast, non-small cell lung, and colorectal cancer and were of high or medium quality as assessed by the Newcastle Ottawa Scale. All studies were from high-income countries, and mostly included patients enrolled in national health insurance systems. Five assessed the impact on treatment delay or adherence, and 25 focused on the receipt of guideline recommended treatment. 20/25 studies demonstrated evidence that patients with pre-existing mental health disorders were less likely to receive guideline recommended therapies such as surgery or radiotherapy. In addition, there was a greater likelihood of receiving less intensive or modified treatment including systemic therapy.

Conclusions: Across different cancer types and treatment modalities there is evidence of a clear disparity in the receipt of guideline recommended cancer treatment for patients with pre-existing mental health disorders. The effect of pre-existing mental health disorders on treatment delay or adherence is under-researched. Future research needs to include low- and middle-income countries as well as qualitative investigations to understand the reasons for disparities in cancer treatment.



## Posters

Alphabetical by first presenting author

### **A rapid systematic review exploring the qualitative experiences of people living with lung cancer in rural and remote areas**

**Nabilah Ali**<sup>1,2</sup>, Dr David Nelson<sup>3,4</sup>, Dr Helene Markham-Jones<sup>3</sup>, Prof Ros Kane<sup>5</sup>, Prof Mark Gussy<sup>3</sup>, Dr Samuel Cooke<sup>5</sup>  
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Background: There is growing evidence to suggest that some rural and remote populations have higher rates of lung cancer incidence and mortality as well as poorer access to treatment when compared to their urban counterparts. This is somewhat a result of variation in socio-economic deprivation. However, there remains limited exploration and understanding surrounding the qualitative experiences of people living with lung cancer who reside in rural and remote areas.

Aim: To conduct a rapid evidence synthesis to explore the qualitative experiences of people living with lung cancer who reside in rural and remote areas.

Methods: Keyword searches were performed in MEDLINE, CINAHL, and PsycINFO. Searches were limited to identify evidence between 2000-2022 and included studies published in the English language only. Whilst no search limits were set on geography, only studies conducted in high income countries as defined by membership of the Organisation for Economic Co-operation and Development were included. The analysis of articles was conducted using the qualitative evidence synthesis approach developed by Thomas and Harden.

Results/Conclusions: Eight articles were included in this review. The analysis of qualitative data identified five overarching themes: (1) experiences with health care professionals, (2) cancer management process, (3) barriers to accessing services, (4) knowledge and awareness of disease, and (5) impact on themselves and others. Our findings suggest that people living with lung cancer who reside in rural and remote areas experience unique challenges related to the management of their condition in addition to the access and quality of care. These findings contribute to a greater understanding of the social and geographical experiences of individuals living with lung cancer which may be used to potentially inform future research and service provisions in addressing the most important health disparities they may face.



### **Understanding the psychosocial support provided by nurses in chemotherapy day unit: A qualitative interview study**

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Background: Chemotherapy nurses are facing increasing workload challenges against the backdrop of rising patient numbers, innovations in systemic anti-cancer therapies and continued development of responsive outpatient chemotherapy systems. This raises concerns about the quality of patient care and has implications for workforce outcomes (e.g., wellbeing, staff retention).

Aim: To explore in-depth specific aspects of chemotherapy day unit (CDU) nurses' work including their roles and responsibilities (e.g., safe chemotherapy administration, symptom assessment, information giving, self-management advice, and psychosocial support).

Methods: 15 qualitative, online, semi-structured interviews were taken, and Framework Analysis was used.

Results: In depth findings about CDU nurse's views on current psychosocial support status for CDU patients will be presented. First, clinical nurse specialists (CNSs) are considered the key contact for CDU patients' psychosocial support. Secondly, the level of the psychosocial support that CDU nurses can provide to the patients highly related to nurse-to-patient ratio. Furthermore, CDU nurses reckon that patients are not receiving adequate psychosocial support through the cancer journey which resulted from the under pressured workforce and the poor patient's referral system. Finally, this study also identified that some CDU patients do not have their CNSs (insufficient CNSs number) therefore they have limited access to all the psychosocial support sources, at the same time CDU nurses do not have the ability to be the key contact, which is a gap that poses a serious threat for the quality of care and patient outcomes in CDU.

Conclusion: This study will provide insights into psychosocial support provided in CDU and will add significantly to the dearth of research on the CDU nurse role.



### **Systematic Review of health literacy interventions to improve earlier diagnosis of cancers of the respiratory system.**

**Jennifer Deane**<sup>1</sup>, Dr Christina Dobson<sup>1</sup>, Prof Gill Rowlands<sup>1</sup>, Prof Joanne Patterson<sup>2</sup>, Dr Fiona Menger<sup>1</sup>, James O'Hara<sup>1,3</sup>, Michael Nugent<sup>4</sup>, Val Bryant<sup>5</sup>, Jennifer Dunbar<sup>5</sup>, Suzanne Miller<sup>5</sup>, R. Barry Phillips<sup>5</sup>, Prof Linda Sharp<sup>1</sup>  
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Background:

Cancer survival rates in the UK are lower than in many other developed countries. This is considered to be due, at least in part, to diagnosis of cancers at a late stage in the UK. Therefore the promotion of earlier diagnosis of cancer has been a priority in successive cancer plans for England.

Health literacy refers to the extent to which an individual has the appropriate skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services. Suboptimal health literacy is common in England. However, health literacy is potentially modifiable. Moreover, health services can be adapted to be more accessible for those with suboptimal health literacy.

There is accumulating, albeit limited, evidence that health literacy influences patient delays in cancer.

Aims: The primary aim of this systematic review was to identify and synthesise health literacy interventions to promote earlier diagnosis of symptomatic cancers. Our secondary aim was to identify whether particular intervention components and characteristics are associated with effectiveness.

Methods: A search strategy was designed with an information specialist. This included terms in four areas; cancer, early diagnosis, health literacy and interventions. The databases searched were MEDLINE, EMBASE, CINAHL, PsychINFO, ASSIA, Web of Science and Scopus. All papers which reported an intervention with the aim of improving the early diagnosis of cancers of the respiratory system (above the diaphragm) were included. To be eligible the intervention had to involve improving health literacy skills. Studies conducted in the context of screening programmes, or which sought only to improve knowledge, were excluded. (PROSPERO registration: CRD42021291038)

Results/Conclusions: Eight papers covering 5 studies were eligible: 2 relating to head and neck cancer and 3 to lung cancer.

Data extraction and synthesis is currently underway. Full results will be ready for presentation at BPOS.



## How 'significant others' support parents with decision-making about their child's cancer care: Findings from an integrative literature review

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Background: Parents are faced with making challenging decisions when their child is diagnosed with cancer which include treatment decisions, supportive care decisions and social decisions. This can create additional stress for parents who are already living through an extraordinarily difficult time. Establishing the support needs of parents is therefore very important. Whilst previous research has explored how health care professionals can offer support, little attention has been given to how informal support may be provided from a parent's network of significant others.

Aims: This presentation will share findings from a literature review that synthesised current evidence about this topic. It will explore how the findings of the review are relevant to health care professionals caring for children and families with cancer and how the findings have informed further research.

Methods: An integrative literature review was conducted. Searches were undertaken using four databases and hand-searching reference lists of retrieved papers. Inclusion and exclusion criteria were applied and studies that met the inclusion criteria were critically appraised. Included papers were analysed using the Constant Comparative Analysis method.

Results / Conclusions: Twenty-six articles were included. Two over-arching themes were identified:

- Dimensions of Decision-Making support considers how support can be provided using informational, emotional and instrumental mechanisms.
- Expectations of Decision-Making support explores how expectations of parents' roles, and the roles of their significant others impacts on the provision of support.

These themes demonstrated that parents may receive support from various members of their social support network, but there is a fine line between what are perceived by parents as supportive and unsupportive behaviours.



## Psychosocial experiences of oropharyngeal cancer patients and of informal caregivers following chemoradiotherapy - two systematic reviews

**Sara Matthews<sup>1</sup>**, Dr Jo Brett<sup>1</sup>, Dr Pras Ramluggun<sup>1</sup>, Prof Eila Watson<sup>1</sup>

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Background: Head and neck cancers (HNC) are the 6th most common cancer type globally. The UK incidence of oropharyngeal cancer, a type of HNC, has risen sharply over the last 30 years with an increase in human papillomavirus (HPV) associated diagnoses, most prevalent in younger, working age populations. Although responsive to chemoradiotherapy, with a good prognosis, severe side effects result in significant psychosocial consequences, such as being unable to share meals with others due to eating difficulties. Patients often rely on informal caregivers during the acute recovery period when care becomes home-based.

Aims: Two systematic reviews have been undertaken to explore the psychosocial experiences of oropharyngeal cancer patients and of their informal caregivers following chemoradiotherapy in order to inform future research.

Methods: Systematic review methods included electronic database searching (e.g., CINAHL, MEDLINE and PsycINFO), study selection criteria, quality appraisal using CASP, and data synthesis.

Results and Conclusions: The completion of chemoradiotherapy signalled a milestone for patients and a transition for caregivers as they took on burdensome responsibilities, alongside other roles. Experiences included having to cope with unexpectedly severe side effects and adapting to a 'new normal'. A difficult and complex recovery meant that despite a favourable prognosis, poor psychosocial well-being may threaten a successful outcome. The experiences of patients and caregivers varied in terms of their trajectory and the support received, leading to differences in knowledge, perceptions, and behaviours. Commonality existed in their need for preparation for life altering experiences to inform expectations and for support for relationships and families, but its nature is yet to be determined.

Heterogenous HNC psychosocial research was found that is limited in oropharyngeal cancer, particularly regarding informal caregivers and does not reflect contemporary UK MDT support, indicating the need for further research.



## Early self-reporting and detection of patients at risk of neutropenic sepsis: impact of patient knowledge, behaviours and health inequalities.

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Background: Neutropenic sepsis (NS) is a life-threatening emergency associated with chemotherapy-induced immunosuppression. At-risk patients must act promptly upon associated symptoms, e.g. fever, as early antibiotics can be life-saving.

Aims: This study evaluates chemotherapy patients', and their carers', abilities to recognise NS, and whether this is affected by specific demographic/socioeconomic features.

Methods: This study consisted of 2 parts. Inclusion criteria included: current/prior chemotherapy patient/carer, any cancer type, age >18.

First, structured interviews were conducted by 52 North (n=15) obtaining qualitative information around NS understanding. Secondly, in collaboration with Macmillan Cancer Support a focused online survey was undertaken (31 eligible respondents to date). Questions included: "I understand what neutropenic sepsis is and how it is relevant for me or the person I care for". A 5-point Likert scale was used. Participant consent was taken (GDPR compliant).

Results/conclusions: Interviews demonstrated potential lack of adherence to NS-related guidance and a complexity of features influencing behaviour. One respondent stated they hesitated calling with isolated fever to avoid burdening healthcare professionals.

From the online survey: male:female - 7:24, ages 31-80 (71% 51-70), patient:carer - 24:7.

Only 17/31 (54.8%) individuals agreed/strongly agreed that they understood NS. 11/31 (35.5%) disagreed/strongly disagreed with 3/31 (9.7%) neutral. 26/31 (83.9%) reported NS-associated symptoms (fever, generally unwell). Of these, only 12/26 (46.2%) sought medical advice <1hr, 6/26 waited >1hr, 7/26 sought no advice, (1/26 – inpatient).

Individuals reporting greater NS understanding were ~3x likelier to seek help <1hr post-symptoms (61.5% vs. 22.2%; 8/13 vs. 2/9). Individuals with salaries >£30K vs. <£30K were ~4x likelier to seek help <1hr (53.8% vs. 14.3%; 7/13 vs. 1/7).

This data demonstrates significant lack of understanding around NS and delays in seeking potentially life-saving care. This appears to be exacerbated by socioeconomic factors, highlighting the need to increase education which may need targeting towards particular at-risk groups.



## Understanding the effects of colorectal cancer surgery on body image and sexual functioning, a meta-analysis

**Claudia Redeker**<sup>1</sup>, Prof Anne Miles<sup>1</sup>, Prof Beth Grunfeld<sup>1</sup>

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Background: The comparison of QoL among CRC patients with and without ostomies indicates no differences in overall QoL. Less researched, but nevertheless, important aspects of QoL are body image and sexual functioning. Body image disturbance and sexual dysfunction are two of the most common issues encountered by CRC patients, caused through either direct pathways (e.g., surgery, injury to the sympathetic or parasympathetic nerves, stoma) or indirect pathways (e.g., emotional, psychological, and social factors) or a combination of both.

Objective: This meta-analysis aimed to examine whether sexual function and body image differ between patients with and without ostomies following colorectal cancer surgery.

Method: A systematic search within 7 databases (MEDLINE, PsychINFO, EMBASE, The Cochrane Library, PubMed, CINAHL, and WEB of SCIENCE) yielded 527 unique studies, of which 75 met the inclusion criteria. Sexual function was assessed by questionnaires (IIEF, FSFI, EORTC QLQ CR29, EORTC QLQ CR38). In addition, the questionnaires EORTC QLQ CR29, EORTC QLQ CR38, and BIS assessed Body image.

Results: Ostomy patients, compared to patients without an ostomy, reported significantly more sexual dysfunction (g=-0.290, p=0.001), more body image concerns (g=-0.586, p=0.001), and less sexual enjoyment (g=-0.197, p=0.003). Sexual functioning (SF), when assessed by two items measuring sexual interest and activity (CR38), no significant

difference between the groups was found ( $g=-0.082$ ,  $p=0.127$ ). However, when SF was assessed with only one question (CR29), namely interest in sexual activity, a significant difference among ostomy patients and patients who had received sphincter-sparing surgery ( $g=-0.183$ ,  $p=0.001$ ) was found.

Conclusions: The current meta-analysis highlights two important issues. Firstly, ostomy patients reported sexual difficulties and body image concerns more frequently than patients without an ostomy. Secondly, sexual interest alone was significantly more often reported among no-ostomy patients. However, no such difference was found when interest in conjunction with activity was assessed.



### **“It’s a delicate dance” How informal caregivers experience the role and responsibilities of supporting someone living with a low-grade glioma**

**Ben Rimmer<sup>1</sup>**, Michelle Balla<sup>1</sup>, Dr Lizzie Dutton<sup>1</sup>, Dr Richéal Burns<sup>2</sup>, Prof Vera Araújo-Soares<sup>3</sup>, Prof Tracy Finch<sup>4</sup>, Dr Joanne Lewis<sup>5</sup>, Prof Pamela Gallagher<sup>6</sup>, Dr Sophie Williams<sup>5</sup>, Dr Fiona Menger<sup>1</sup>, Prof Linda Sharp<sup>1</sup>

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Background: Low-grade gliomas (LGG) are rarely cured and almost always progress, limiting patient life expectancy to 5-15 years. Patients are often in the 30s or 40s at diagnosis. They may require support to manage the significant symptom burden (e.g. fatigue, cognitive deficits) associated with the tumour and its treatment. Partners, family-members, and friends often assume the role of informal caregiver (IC), but the types of support they provide, and their experience of this, has not been well investigated.

Aims: We aimed to explore how ICs experience the role and responsibilities of supporting an LGG patient, to understand what and how support is provided, and any associated challenges.

Methods: This cross-sectional, qualitative study used semi-structured interviews to explore the role and responsibilities of ICs who currently, or in the past five years, supported someone with an LGG diagnosis. Interviews were audio-recorded, transcribed and coded. We conducted a thematic analysis.

Results/Conclusions: Nineteen ICs were interviewed (mean age 54.6 years; 5 males, 14 females). While most participants identified as a ‘carer’, the perceived level of care required by the care recipient varied. Participants reported their experiences with providing cognitive (e.g. implementing strategies to help with memory), emotional (e.g. providing companionship), and practical (e.g. support with daily living) support, and helping to navigate the healthcare system. They described many challenges they experienced with fulfilling their caring role and responsibilities (e.g. trying not to limit the care recipient’s independence; conflict with work/childcare), feeling ‘abandoned’ to provide the required care themselves.

ICs of LGG patients can offer wide-ranging support to help patients manage the consequences of their illness; largely fatigue, cognitive deficits, and the emotional impact. Consideration of ways to support ICs, and manage the challenges they face in their caring role, could help improve experiences and outcomes of LGG patients.



### **How perceptions of candidacy shape help-seeking behaviour and diagnostic and treatment experiences for colorectal cancer patients.**

**Fathima Masha Fazlath Roomie<sup>1</sup>**, Prof Linda Sharp, Dr Christina Dobson

<sup>1</sup>Newcastle University

Background: Colorectal cancer (CRC) is the third-most common cancer globally. Candidacy explains how people appraise, assess and act upon their perceived risk of a disease. The limited research applying the concept of cancer candidacy, focused on screening and perceptions of cancer risk in the general population.

Aims: This research aimed to explore the impact of candidacy on CRC patients’ diagnostic pathways, focusing on the perceptions of risk at different points in this pathway, considering how it impacted decision-making and experience.

Methods: Secondary analysis of semi-structured interviews (19 CRC patients; X screen-detected, Y symptomatic) from the COVID/CRC study (which examined experiences of being diagnosed with CRC during the Covid-19 pandemic), applying the concept of candidacy.

The transcripts were analysed using reflexive thematic analysis as it is embedded on emerging themes and patterns of meaning while at the same time considering the active role of the researcher in the production of knowledge.



Findings: Three main themes were identified:

1. Being a cancer candidate: Participants with a family history of cancer saw themselves as cancer candidates, whereas participants who rejected candidacy did so as they viewed themselves as “healthy”.
2. Re-assessing: After the diagnosis, participants experienced a re-framing of their identities, with all participants experiencing a “biographical disruption”. Irrespective of earlier perceptions of candidacy, or their route to diagnosis (i.e., screening, or symptomatic routes) participants experienced a phase of “shock” and “fear” upon diagnosis.
3. Accommodating cancer: Patients are forced to accommodate cancer into their identities: some were more accepting and positive about life (spending more time with their family/travelling), whereas others had to unwillingly accommodate cancer, often struggling with the changes to their lives, for instance dealing with a stoma.

These findings suggest incorporating concepts of cancer candidacy into cancer prevention and survivorship initiatives could be of value.



## **A pragmatic cluster randomised controlled trial (RCT) assessing the clinical and cost effectiveness of electronic risk-assessment tools (eRATs) for cancer for patients in general practice: An ERICA trial overview.**

**Dr Elizabeth Shephard<sup>1</sup>**, Dr Raff Calitri<sup>1</sup>, Prof Sarah Dean<sup>1</sup>, Prof Willie Hamilton<sup>1</sup>, The ERICA Trial Team<sup>1</sup>

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Background: The UK has poorer cancer survival outcomes compared with other developed countries. With an increase in undiagnosed cancer following Covid-19, NHSE policy mandates adoption of cancer risk tools in primary care. Previous work produced tools to calculate the risk of undiagnosed cancer in patients with specific clinical features. These tools have been converted into electronic format to incorporate into clinical systems for six cancer sites.

Aims: To assess the clinical- and cost-effectiveness of using electronic Risk Assessment Tools (eRATs) to facilitate the early diagnosis of cancer in primary care. Process evaluation aims to investigate factors impacting the effectiveness of the eRATs for fidelity and GP engagement, plus the impact on patients.

Methods: ERICA is a pragmatic, cluster RCT of 530 general practices across England randomised 1:1 to receive either the intervention (eRATs medical device embedded in the clinical system) or usual care. The suite of six eRATs generate a pop-up alert detailing a personalised cancer risk score when a patient has a 2+% risk of bladder, kidney, lung, colorectal, oesophago-gastric or ovarian cancer. The clinician decides the appropriate course of action following the pop-up. The primary outcome collected from English cancer registry data (available in 2025) will be the stage of cancer at diagnosis. A 4-5% increase in early-stage cancers diagnosed (stages 1-2) versus late-stage cancers (stages 3-4) during the 2-year trial period is aimed for. Underpinned by the COM-B framework, the parallel process evaluation explores practice and GP use of eRATs, plus patient experience of care, through qualitative interviews.

Results: Recruitment has ceased; 439 practices have been randomised. Process evaluation interviews have begun.

Conclusions: The eRATs may assist primary care clinicians in identifying sooner which patients warrant specialist referral for undiagnosed cancer and to which speciality. Understanding the contextual factors impacting eRAT uptake is important for policy guidance.



## **Perceptions and experiences of the subjective wellbeing of people with a diagnosis of glioblastoma: a longitudinal phenomenological study.**

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Background: Glioblastoma (GBM) is a devastating form of brain cancer with a short life expectancy. In addition to this poor prognosis, people with GBM often experience symptoms resulting from cognitive deficits, which may have a profound impact on their subjective wellbeing (SWB).

Aims: The aim of this study was to investigate the lived experiences and perceptions of people with high GBM regarding their subjective wellbeing (SWB).

The objectives were:

- To explore the lived experiences and perceptions of people with GBM in terms of their SWB at various points throughout their illness.
- To clarify the meaning of the term ‘wellbeing’.

- To investigate the lived experiences and perceptions of people with GBM regarding the assessment tools currently used to monitor their SWB.

Method: Twenty-seven interviews were conducted with 15 patients over a period of two years. The majority of participants were interviewed twice on a face-to-face basis (shortly after surgery, and again following the completion of adjuvant treatment). The study adopted a longitudinal, hermeneutical phenomenology approach. Data were managed using NVivo 10 software and analysed using the Hermeneutic Circle.

Conclusions: Analysis of the data identified four key domains in relation to the study aims. These were 'daily life', 'experiences of care', 'psychological wellbeing' and 'health'. Each of these domains consisted of multiple themes, which were then critically analysed for their potential to threaten the SWB of people with GBM. Interpretive phenomenological analysis of the data identified a conceptual framework for SWB encompassing three key domains that appeared to be most relevant to participants. These were Hope, Sense of Identity and Sense of Control. The nature of these domains fluctuates over time as they are subjected to a variety of threats resulting from GBM diagnosis and treatment.



## **Does prehabilitation provide a model for holistic long-term care? Early insights from a lung cancer feasibility study**

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Introduction: There is significant potential to improve outcomes for lung cancer patients in terms of quality of life and survival. There is some evidence that surgical prehabilitation can support both aims. Models of prehabilitation may provide a framework to deliver holistic care. Currently up to 80% of lung cancer patients do not receive primary surgical resection and so miss out on the potential benefit of a holistic approach. We co-designed a personalised and evidence-based prehabilitation programme, which draws on a conceptual framework that aligns with patient values and needs as well as functional goals. Here, we present early insights and reflections from our feasibility study.

Methods: A feasibility study incorporating quantitative assessments, a qualitative free text questionnaire and reflective field notes. All recruited patients receive a personalised prehabilitation programme during their oncological treatment. This includes a one-hour face-to-face appointment prior to, at week three and at week six of their treatment regimen as well as a weekly telephone call. Interventions including nutrition, physical activity and psychological wellbeing are stratified according to a patient's priorities, level of readiness and expressed needs.

Preliminary findings: Alongside the quantitative assessment findings, early insights demonstrate the importance of a person-centered approach.

Our model offers a means of tailoring psycho-social support for lifestyle change by understanding and responding to what matters most to the individual. This provides a practical framework to deliver holistic care. This feasibility study demonstrates the value of an early individualised framework of holistic care, described as prehabilitation in non-surgical cancer patients.



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