



British Psychosocial Oncology Society

# Annual Conference 2026

Holiday Inn - Bristol City Centre



## Abstract Book

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*Last updated 23/02/2026*

# Session 1: Diagnosis and Prehabilitation

## Associations between diagnostic time intervals and quality of life, clinical anxiety and depression in adolescents and young adults with cancer: cross-sectional analysis of the BRIGHTLIGHT cohort

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Background: Compared to children and older adults, adolescents and young adults (AYA) with cancer experience prolonged diagnostic intervals. The impact on outcomes is poorly understood due to a lack of systemic investigation in AYA.

Aims: We investigated diagnostic intervals and their association with quality of life (QoL), clinical anxiety and depression in a large AYA cohort.

Methods: The BRIGHTLIGHT study recruited 1,114 participants, aged 13-24 at diagnosis during 2012-2014, from 97 English hospitals. Participants completed face-to-face interviews 4-7 months post-diagnosis, providing data on diagnostic experiences and patient-reported outcomes (PROs). Demographic and cancer information were obtained from clinical and national records.

Six diagnostic interval measures were considered: symptom onset to General Practitioner (GP) appointment ('patient interval', <1 versus >1 month); GP pre-referral consultations (n=1-2 versus >3); symptom onset to first oncology appointment ('symptom onset to oncology'; <2 versus >2 months); symptom onset to diagnosis ('symptom onset to diagnosis'; weeks 0-4; 5-11; ≥12); symptom onset to treatment initiation ('total interval'; <91 versus ≥91 days) and diagnosis to treatment ('treatment interval'; ≤31 versus >31 days).

PROs, measured with validated instruments, included QoL (high risk of impaired QoL/low risk), anxiety and depression (not depressed/anxious; clinically depressed/anxious; severely depressed/anxious). Relationships between intervals and PROs were examined using regression models.

### Results:

830 participants completed interviews. In adjusted models, consistently across 28/30 associations, longer intervals were associated with poorer PROs. Patient intervals of ≥1 month were associated with greater clinical depression (adjusted odds ratio (aOR):1.7, 95% Confidence Interval (CI):1.1-2.5). Three or more pre-referral GP consultations were associated with greater clinical anxiety (aOR:1.6, CI:1.1-2.3). 'Symptom onset to oncology' intervals of ≥2 months, were associated with impaired QoL (aOR:1.8, CI:1.2-2.5).

### Conclusion:

Longer diagnostic intervals in AYA are associated with an increased risk of impaired QoL, anxiety and depression. Identifying and delivering interventions for this high-risk group is a priority.



## ◆ Improving the ROUTE to diagnosis of lung cancer in people who have never smoked

**Dr Sally Taylor**<sup>1,2</sup>, Grant Punnett<sup>1</sup>, Bobby Bhartia<sup>3</sup>, Dr Georgia Black<sup>4</sup>, Dr Stephen Bradley<sup>5</sup>, Dr Louise Brown<sup>6</sup>, Dr Mat Callister<sup>7</sup>, Sally Hayton, Ramsay Lochhead-Devaraj<sup>1</sup>, Prof Rachael Murray<sup>8</sup>, Dr Samantha Quaife<sup>4</sup>, Dr Sarah Taylor<sup>9</sup>, Prof Janelle Yorke<sup>10</sup>, Prof Matthew Evison<sup>11</sup>

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Background: Approximately 10-20% of lung cancer cases occur in people who have never smoked. Strong associations of lung cancer with smoking, screening program eligibility and reduced likelihood of referrals for people with respiratory symptoms who have never smoked, contribute to diagnosis delays. Education campaigns should raise awareness of lung cancer amongst people who have never smoked but should not undermine tobacco control messaging.

Aim: To develop strategies to: 1) encourage people (particularly those who have never smoked) to recognise potential lung cancer and encourage them to take action; 2) ensure the healthcare system responds appropriately to maximise chances of earlier diagnosis.

Methods:

- 1) Focus groups with 14 people who have never smoked to discuss lung cancer awareness, help-seeking behaviours and campaign messaging
- 2) Interviews with 20 people who smoke to ensure messaging does not destabilise stop smoking campaigns
- 3) Focus groups (n=tbc) with primary care professionals to explore challenges to diagnosis and potential improvements. Data will be analysed thematically.

Results: Phase 1: Initial analysis highlights the strong association of lung cancer with smoking. Participants were surprised by some symptoms and felt many were not concerning individually. If unwell, participants often self-managed for 2-3 weeks before seeking help. Awareness campaign messaging should include: importance of early detection, emphasising everyone is at risk, potential symptoms, help-seeking timing, self-advocacy advice.

Phase 2: Initial analysis suggests most messages would not detract from stop smoking campaigns and may even encourage smoking cessation. Phase 3: recruitment is ongoing.

Conclusion: Preliminary findings highlight limited awareness of lung cancer amongst people who have never smoked. Campaigns should empower people to take action and provide specific advice about symptoms, when to seek help and how to navigate NHS systems. Messaging focusing on the risk of smoking amongst people who have never smoked would not negatively affect stop smoking campaigns.



## **Exploring Patient Experiences and Perspectives on Psychological Readiness for Surgery through Prehabilitation and Treatment**

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Background: Cancer diagnosis and treatment can significantly affect physical and psychological wellbeing, with distress linked to poorer health outcomes and becoming more difficult to treat once established. This highlights the need for preventative approaches to psychological care. Cancer prehabilitation provides a valuable window to address psychological wellbeing early. However, current models of psychological prehabilitation overlook patients lived experiences and needs for psychological readiness.

Aims: The primary aim of this study was to explore patients' meanings, emotions and expectations about their psychological readiness for surgery through prehabilitation and treatment.

Methods: A longitudinal qualitative design using semi-structured interviews was conducted. Ten participants completed two semi-structured interviews, one during the prehabilitation period and one after surgery. Themes were generated using a semantic inductive reflexive thematic analysis approach to analyse all interviews. A longitudinal analysis was then conducted to analyse change and stability over time.

Analysis: All ten participants took part at T1 and T2. One overarching theme was constructed "The mindset to have surgery": Components of Psychological Readiness (PR), with three main themes: "Her intel was priceless to me": Reliable and Complete Information; "You know you're not alone": Supported by and Supporting each other, and; "What's the thing that I can do?": Patient as Active Agents in their Treatment.

Conclusions: The themes generated in the current study broadly aligned with previous research outlining patient psychological support needs during cancer treatment. The current study adds to the literature by exploring how participants define psychological readiness and how prehabilitation can support its development.



## **Incorporating Psychology into Prehabilitation pathways improves Psychological and Functional Outcomes for patients**

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Background: Patients facing surgery often experience significant psychological difficulties, negatively impacting physical recovery. Including psychology in multimodal prehabilitation support for cancer patients can enhance a range of post-surgery outcomes and is recommended by Macmillan’s Prehabilitation Guidance (2025). However, most prehabilitation services are not commissioned to provide holistic care. Therefore, the East Midlands Cancer Alliance Centre for Psychosocial Health developed a rapid-response pathway, providing remote psychology sessions pre- and post-surgery, in collaboration with regional prehabilitation services.

Aim: This study explores the effectiveness of embedding psychology support in cancer prehabilitation.

Methods: Quantitative analyses:

- 1) compared cancer patients with severe mental health difficulties, who accessed psychology (n=60) versus those who declined (n=418), on depression (PHQ-9), anxiety (GAD-7) and functioning measures (e.g. strength and fitness), pre- and post-prehabilitation for major surgery;
- 2) compared GAD-7 and PHQ-9 scores in patients (n=135) pre and post-psychology sessions.

A thematic analysis is underway on interviews with 15 patients who attended psychology sessions, analysing their experience of therapy.

Results: Quantitative results suggest whilst improvements were seen in all prehabilitation patients ( $p < .001$ ), larger effect-sizes were observed in PHQ-9, GAD-7, and sit-to-stand scores (SMDs: 1.02 vs. 0.80, 1.09 vs. 0.94, and 0.87 vs. 0.64 respectively) for those accessing psychology support. Those accessing psychology experienced similar improvements in average anxiety and depression scores as national NHS Talking Therapies, but in fewer sessions (on average 5.5 versus 8.4) (PHQ-9 MD=6.81, 95% CI[5.09, 8.53],  $p < .001$ ; GAD-7 MD=8.79, 95% CI[7.02, 10.56],  $p < .001$ ).

Initial qualitative results suggest patients found psychology support highly valuable in preparing for and recovering post-surgery and enhanced other prehabilitation input (e.g. exercise interventions).

Conclusion: Findings indicate that embedding psychology in multimodal prehabilitation enhances benefits to both psychological and functional outcomes for cancer patients. Future plans involve a prehabilitation Randomised Control Trial comparing outcomes for those who do and do not access psychology.



## Session 2: Populations with Complex Needs

### Cancer diagnosed during pregnancy: women's psychosocial experiences from diagnosis to survivorship

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**Background:** Cancer diagnosed during pregnancy is increasing, yet the psychosocial impact of navigating cancer treatment alongside pregnancy, birth and early motherhood remains underexplored in the UK. Understanding these experiences is essential for improving psychological care and survivorship support.

**Aims:** To examine the emotional, psychological, and practical challenges faced by women diagnosed with cancer during pregnancy and the postnatal period, and to identify implications for supportive care.

**Methods:** Twenty women across the UK who received a cancer diagnosis during pregnancy or shortly postpartum were recruited via the charity Mummy's Star. Semi-structured online interviews (36–66 minutes) explored experiences from the point of diagnosis to survivorship. Data were analysed using template analysis, informed by prior diagnostic-pathway work, a scoping review, and preliminary coding. A multidisciplinary team iteratively refined the themes.

**Results:** Six interrelated themes captured women's psychosocial trajectories: (1) Managing cancer with constrained choices; (2) Ethical decision-making; (3) Balancing cancer and family life; (4) Work and financial strain; (5) Emotional impact and (6) Coping and support. These will be discussed in detail.

**Conclusion:** Women diagnosed with cancer in pregnancy face profound and enduring psychosocial challenges, exacerbated by fragmented oncology–maternity care. Psychological support was inconsistently available and often poorly timed for women's readiness. Findings highlight the need for integrated multidisciplinary pathways and flexible psychological support extending into survivorship. Given the complexity and contextual nuance of delivering coordinated care, future work should also include realist evaluation to understand how specific contexts and mechanisms shape outcomes in practice. Further research should investigate factors impacting optimal multidisciplinary care delivery, long-term psychological outcomes, and evaluate interventions tailored to this population.



### ◆ Understanding the Cancer Diagnosis Pathway: Experiences of Adults with a Learning Disability and Those Who Support Them: A Qualitative Study

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**Background:** Adults with a learning disability experience marked health inequalities, including delayed cancer diagnosis and poorer outcomes. Cancer is now a leading cause of preventable mortality in this population, yet limited evidence explores lived experiences of the diagnostic pathway.

**Aim:** This study seeks to understand how adults with a learning disability, and advocates who support them, navigate the pathway to cancer diagnosis, and how psychosocial, relational and structural factors shape experiences.

**Methods:** Semi-structured interviews were conducted with adults with a learning disability (n=5) and advocates/supporters (n=5). Accessible research materials were co-developed with a Patient and Public Involvement and Engagement (PPIE) panel. Recruitment required over one year of relationship-building with advocacy organisations. Data were analysed using reflexive thematic analysis, supported by the concepts of

Candidacy and Health Stigma and Discrimination Framework to illuminate how access, recognition of need, and social power dynamics shaped participants' pathways to diagnosis.

Findings: Across the integrated dataset, three overarching themes were developed. (1) Understanding lives, context and identity described the importance of seeing the whole person and recognising need, and the pervasive weight of stigma, rooted in intersecting identities. (2) Navigating the healthcare system captured systemic gaps and delayed diagnoses, communication and technological barriers, challenges to autonomy, and the critical but emotionally demanding role of advocacy in securing care. (3) Envisioning the future: compassion, partnership and transformation highlighted examples of compassionate practice, the value of relational continuity, and a call for inclusive, co-designed systems driven by training, shared learning and workforce development.

Conclusions: The study highlights enduring barriers to timely cancer diagnosis for people with a learning disability, alongside examples of effective and compassionate care. Findings underscore the need for policy and practice transformation grounded in accessibility, partnership, and anti-stigma approaches. Co-produced dissemination and ongoing PPIE involvement will support translation into clinical and psychosocial oncology settings.



### **“The World Stopped”: Exploring the views and experiences of people diagnosed with lung cancer who have never smoked**

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Background: The diagnosis of lung cancer in individuals who have never smoked (LCINS) is increasing, and currently accounts for 15% of lung cancer cases in the UK. LCINS are associated with a range of environmental risk factors as well as oncogenic mutations such as EGFR or ALK. A better understanding of the care experiences and psychosocial needs of those diagnosed with lung cancer who have never smoked is required.

Aims: The aim of the ENHANCE study was to explore the views and experiences of those diagnosed with lung cancer who have never smoked.

Methods: This mixed methods study involved an online survey (n=80) and interviews (n=24) with people with lung cancer who have never smoked. Qualitative data were analysed thematically using the Framework Method. Survey data were analysed descriptively, and associations between stigma and quality of life were explored.

Results: The importance of holistic and relevant support and information appropriate to the life stage of a younger, active patient cohort (e.g., help with childcare, work, travel), as well as the chance to build support networks around shared experience, was emphasised. The need to support patients with the significant emotional impact of diagnosis, and the impact of stigma on psychological functioning and quality of life was highlighted. Increasing awareness amongst healthcare professionals and the public could improve delays in diagnosis and feelings of isolation.

Conclusion: People diagnosed with lung cancer who have never smoked have specific care and support needs. Quality of life and experiences of care could be improved through better information and enhanced psychosocial support across different stages of the care pathway. Further research is required to develop targeted, patient-centred interventions to meet the needs of this group.



# Understanding Adjuvant Endocrine Therapy Experiences Among Black Women in the UK: A Qualitative Study

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**Background:** Despite the effectiveness of adjuvant endocrine therapy (AET) in reducing oestrogen-receptor-positive (ER+) breast cancer recurrence, lower adherence and higher mortality rates persist among Black women in the UK. Limited research has explored their lived experiences, particularly the unique ways AET side effects, beliefs about medication, and interactions with healthcare and support systems shape treatment decisions.

**Aims:** This study explores UK Black women's AET experiences, examining treatment perceptions, adherence influences, and engagement with healthcare and support services.

**Methods:** This qualitative study recruited Black women with ER+ breast cancer through social media, community networks, and NHS outpatient clinics. Semi-structured interviews were conducted by telephone or online and are currently being analysed using inductive thematic analysis.

**Results:** 19 Black women participated (mean age = 48.7 years). Initial themes include: (1) Balancing AET benefits and burdens, with challenging side effects acting as barriers to adherence and affecting identity. Some reported perceived differences in side effects experienced as Black women, including more visible hyperpigmentation and hot flushes on darker skin. Fear of recurrence strongly motivated continuation; (2) Medication beliefs and treatment expectations, where broader perceptions about medicines (e.g. dislike of taking medication) sometimes conflicted with adherence decisions; many chose to adhere due to AET's perceived importance; (3) Navigating healthcare communication and understanding, with limited explanations from healthcare professionals about AET, and a lack of attention to concerns important to Black women, e.g. slowed hair regrowth. Many felt unprepared for the impact of AET and sought information further independently; and (4) The value of culturally grounded support, with Black-led charities offering culturally sensitive support. Some described isolation within mainstream breast cancer groups, where their experiences were less understood.

**Conclusion:** These preliminary findings highlight how culturally specific challenges can shape AET journeys for Black women and emphasise the need for tailored communication and more inclusive support pathways.



## ◆ “What impact does a co-occurring serious mental illness (SMI) have on cancer outcomes?”

**Eimear Lacey**<sup>1</sup>

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**Background:** Patients with serious mental illness (SMI) are known to have worse health outcomes and mortality rates. Despite the relative frequency with which people are diagnosed with both cancer and mental illnesses, the overlap between the two phenomena is not well studied, and the focus of research on this topic is broadly with regards to mental health problems as a sequela of a cancer diagnosis, rather than comorbid conditions that pre-exist the cancer diagnosis.

**Aim:** This review aimed to investigate the impact that a diagnosis of SMI has on cancer outcomes and critically analyse the recurring themes in the literature.

**Methods:** A single-author systematic review was conducted using the Ovid search platform, accessing the PubMed, Embase, and PsycINFO databases. Studies were assessed for suitability for inclusion in this review. Thematic analysis was used to analyse and collate the findings of the current body of research.

**Results:** In total, 2543 articles were identified, of which 1996 were deemed irrelevant, and a further 360 duplicates were removed. During screening, 177 out of 186 articles failed to meet the inclusion criteria.

Therefore, nine articles were included within this review. Three major themes were identified: diagnostic disparities, treatment disparities and excess mortality- both all-cause and cancer specific.

Conclusion: This review highlighted that patients with SMI and cancer are at a higher risk of late diagnosis, premature death and are less likely to undergo guideline recommended treatment. While further research is necessary to understand exact causes and barriers these patients face, action is also needed to educate both patients on the importance of cancer screening and treatment, and clinicians on the complex needs of these patients. Better integrative care between mental health and oncology teams managing these patients is also indicated, to ensure adequate support from diagnosis through to treatment and follow up.



### **Advanced illness and financial insecurity – the Unreached study**

**Prof Lynn Calman**<sup>1</sup>, Dr Jo Williams<sup>1</sup>, Dr Michelle Myall<sup>1</sup>, Dr Naomi Richards<sup>2</sup>, Dr Caroline Mogan<sup>3</sup>, Dr Sam Quinn<sup>4</sup>, Prof Mari Lloyd-Williams<sup>3</sup>

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Background: People with advanced illness often experience prolonged financial insecurity due to reduced income and rising essential costs. Geographic context intensifies these challenges.

Aims: To explore the lived experiences of financial insecurity across diverse settings to inform policy and practice at the end of life.

Methods: This qualitative study explored financial insecurity during advanced illness across three geographical regions in the UK: Scotland (all regions including rural and island communities), rural North Wales and south-central urban England. Using purposive sampling, a total of 51 people (Scotland n=20, North Wales n=18, southern England, n=13) were recruited via community organisations and social media. Participants were interviewed via an in-depth singular digitally recorded meeting (in person, by telephone or video) June 2024 - May 2025. Transcripts were coded iteratively and analysed using the Framework Method to increase validity and reduce bias.

Results: Analysis of interviews (18 people living with advanced illness; 33 family carers), captured experiences resulting in five key themes: (i) difficulties maintaining homes that were not able to be adapted to suit need, compounded by high utility costs (ii) welfare benefits were essential but complex and stigmatised, complicated by administrative, bureaucratic barriers with eligibility gaps deepening hardship (iii) additional expenses (transport, food, care, funeral costs) intensified financial strain (iv) reduced work and pension contributions inflicted enduring insecurity and long-term financial impact (v) community help was inconsistent; outsider status limited access to support, resulting in stigma and isolation.

Conclusion: Financial insecurity compounds the challenges of advanced illness, creating precarity shaped by geography, access to care, and community context. While people adopt strategies, systemic gaps leave many susceptible to ongoing hardship. Normalisation within communities should not be accepted as inevitable. Secure housing, adequate welfare, and affordable living costs represent minimum requirements to maintain independence at the end of life and reduce distress.



## Session 3: Adolescent and Young Adults

### ◆ Understanding Post-Cancer Treatment Support for Teenagers and Young Adults: Insights from the Support My Way Co-Design Project

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Background: After cancer treatment, teenagers and young adults (TYAs) often face heightened support needs as they process the impact of their experience while managing ongoing physical and psychosocial effects. Unlike children, who receive prolonged monitoring for late effects, TYA follow-up care is typically stratified by disease type and often delivered remotely. While treatment completion brings relief, it can also feel unsettling. Many TYAs report feeling unprepared for life after treatment, particularly when regular contact with healthcare professionals ends.

Aims: To explore TYAs' post-treatment support needs at a UK hospital and identify their preferences for timing and delivery of support.

Methods: This two-phase study included: Phase 1, semi-structured interviews with 16 TYAs (aged 16–25 at treatment completion), conducted 1–6 years post-treatment, exploring experiences of support and future care preferences; and Phase 2, co-design workshops with 8 TYAs and feedback from 5 healthcare/allied professionals to refine recommendations.

Results: Phase 1 generated six themes:

- 1) Survivorship as disrupted continuity;
- 2) Negotiating legitimacy and relational safety in help-seeking;
- 3) Support offered vs. support sought: referral pathways and self-initiation;
- 4) Emotional readiness as context-dependent and non-linear;
- 5) Support as an ecosystem rather than a single moment; and
- 6) Personalised autonomy in engagement.

Phase 2 informed recommendations for ongoing, flexible, personalised, and accessible support, with adaptable pathways responsive to changing needs. Healthcare professionals endorsed this approach but noted challenges due to fragmented systems and resource constraints.

Conclusion: TYAs have diverse, often complex support needs after treatment, with many seeking help years later but not always initiating it. Preferences and access pathways vary, highlighting the need for personalised, re-offered support. Partnering with TYAs is essential to design responsive models of care. Future research should adopt co-design methods to develop and evaluate innovative, flexible approaches that evolve with this population.



### ◆ “It made me think”: Results of a co-designed prototype teaching intervention on triadic communication for clinicians working with teenagers and young adults with cancer

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Background: Clinical communication is important to young people and professionals. It was a striking theme in a UK survey of research priorities for adolescents and young adults with cancer (AYAC). Moreover, professionals find communicating with AYAC challenging, exacerbated by limited communication skills teaching.

**Aims:** We sought to understand the communication experiences of all three parties within the triadic encounter. Our aim was to co-design and deliver a prototype teaching intervention to professionals and evaluate it.

**Methods:** This is a large qualitative co-design study. The results of the qualitative data (phase A) were used to co-design a teaching intervention (phase B). The prototype teaching was delivered to twelve professionals (Phase C). This has been evaluated (phase D) in semi-structured interviews. Interviews were digitally recorded and analysed using framework analysis.

**Results:** One learner said:

“Sometimes I might let the third person talk over them, it made me think, I can redirect the questions”

Four key themes were identified:

1. **Learners:** reflected they enjoyed the teaching and had increased awareness and confidence when communicating in the triad.
2. **Teaching:** structure and skilled facilitation of the teaching enabled learners to interact and engage throughout. The clinical vignettes, case scenario and group discussion were a highlight.
3. **Learning:** was hugely relevant and had a potential impact on their clinical practice. The multidisciplinary team approach and virtual learning platform were effective.
4. **Time:** learners and teachers wanted more time to discuss and explore in more depth and to include experiential learning. Teachers were concerned they cut short rich discussion.

**Conclusion:** The prototype teaching was highly relevant and useful for learners, and they wanted more. The timing could be extended to offer the opportunity to practice and receive feedback. Future feasibility testing of this teaching is necessary and could include testing outside of oncology.



## **BRIGHTLIGHT: A decade of change between the 2012 and 2021 teenage and young adult cancer cohorts**

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**Background:** Teenage and young adults (TYA) with cancer experience unique clinical and psychosocial challenges. Over the past decade, significant developments in cancer care, policy, and wider societal change (including the COVID-19 pandemic) may have influenced the experiences and outcomes of this group. The BRIGHTLIGHT study provides an opportunity to explore these shifts through a descriptive comparison of two distinct national cohorts of TYA with cancer recruited in 2012 and 2021.

**Methods:** This descriptive analysis compares baseline data from two BRIGHTLIGHT cohorts: 830 participants recruited between July 2012 to December 2014, and 240 participants recruited between March 2021 and December 2022. Descriptive statistics summarise changes in demographic, clinical, and psychosocial characteristics, and patient-reported outcomes (quality of life [QoL], mental health, and psychosocial support access). These cross-cohort comparisons may reveal emerging trends in TYA cancer care and wellbeing, providing a foundation for hypothesis generation.

**Results:** Demographic and clinical profiles shifted over time. The 2021 cohort was slightly more ethnically diverse and socioeconomically deprived. Clinical indicators suggested improved prognostic profiles, with “good” prognostic scores increasing from 55% (2012) to 76% (2021). However, while clinical nurse specialist support remained high, access to professional psychosocial services declined (75% in 2012 to 49% in 2021). Perceived social support declined markedly from friends, family, and significant others. QoL declined across all domains (physical, emotional, social, school/college/university/work, and psychosocial). Furthermore, anxiety and depressive symptoms increased over the same period.

**Conclusion:** Psychosocial wellbeing and access to psychosocial support among TYAs with cancer has declined over time, despite sustained clinical input. These trends call into question the influence of system-level and societal changes on patient experience.



## ◆ BRIGHTLIGHT\_2021: mixed methods evaluation of teenage and young adult cancer care in Britain

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**Background:** Specialist care is provided in the UK for teenagers and young adults (TYA:16-24 years at diagnosis). Principal Treatment Centres (PTCs) deliver enhanced care exclusively within the PTC or as 'joint-care' with designated hospitals (DH). Central to this is the TYA multidisciplinary team (MDT) and an outreach model co-ordinating care between hospitals.

**Aims:** Compare TYA experiences of care with healthcare professionals (HCP) perspectives of the service they deliver.

**Methods:** A parallel mixed methods study across England, and Wales. Patient experiences and outcomes of care were collected via a cross-sectional survey. HCP perspectives of how care was delivered was collected through a rapid ethnography.

**Results:** A total of 250/1056 (24%) TYA responded. Overall, 200 (80%) rated their treatment teams as excellent or good for helping them prepare for treatment. There was a significant trend of decreasing support in those who only had care in a DH from the TYA CNS ( $p=0.04$ ), youth support coordinator ( $p=0.03$ ) and social worker ( $p=0.04$ ). Significant trends in favor of all-TYA-PTC and joint-care were also observed for educational mentor ( $p<0.006$ ), support from a dietician ( $p=0.004$ ). Support from other MDT professionals was suboptimal across all places of care. Less than half received support from psychologist/counsellor. Forty-nine professionals participated. They were more critical in their interpretation of the care they delivered highlighting inequity in resources and challenges in pathways and co-ordination.

**Conclusions:** Support from the TYA CNS was high, most likely because all of the participants were known to the TYA-MDT due to our recruitment method suggesting that when TYA are known to the TYA-MDT, it facilitates co-ordination of age-appropriate outreach services for young people not being treated solely in the PTC and potentially underlies why there is no difference in outcomes based on location of care.



## **Measuring what matters to adolescents and young adults (ayas) with cancer: introducing the world's first comprehensive quality of life instrument for AYAs, the EORTC QLQ-AYA30**

**Dr Samantha Sodergren**<sup>1</sup>, Dr Olga Husson, Dr Silvie Janssen, Prof Gudrun Rohde, Dr Jamal Hossain, Ms Haneen Abaza, Dr Ali Alkan, Prof Irit Ben-Aharon, Dr Line Bentsen, Prof Marianne Guren, Dr Giorgios Ioannidis, Dr Hiroto Ishiki, Dr Michael Koehler, Dr Emma Lidington, Prof Iwona Ługowska, Dr Manjanuth Nookala Krishnamurthy, Dr Fiona McDonald, Prof Alessandra Majorama, Dr Nikolaos Memos, Dr Maria Otth, Prof Helle Pappot, Dr Marta Perez Campdepados, Prof Duska Petranovic, Prof Katrin Scheinemann, Dr Anna Sikora-Koperska, Prof Dan Stark, Prof Serdar Turhal, Dr Jeanette Winterling, Prof Noam Yarom, Prof Anne-Sophie Darlington

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**Introduction:** Receiving a cancer diagnosis during adolescence or young adulthood (AYA) disrupts critical developmental milestones which can profoundly affect quality of life (QoL). Existing QoL instruments for AYAs often fail to capture these domains adequately.

**Aims:** To develop a European Organisation for Research and Treatment of Cancer (EORTC) questionnaire, that measures QoL issues relevant to AYAs aged 14–39 years with cancer.

**Methods:** Following EORTC Quality of Life Group guidelines for questionnaire development, AYAs undergoing treatment or receiving palliative care completed a draft questionnaire and rated each item for relevance and importance. Participants provided feedback on missing topics, wording, and irrelevant and

unacceptable items. Questionnaire performance was assessed using predefined decision rules, and exploratory factor analysis conducted to identify sub-scales.

Results: The study included 253 AYAs from 19 countries (mean age = 25.51 years, SD = 7.54; 51% male; 81% on treatment; 79% curative intent). The most frequently endorsed issues were realization of priorities (89%), lack of energy (84%), and motivation to live life fully (80%). Fertility and body image emerged as high-priority topics, while loss of friendships and weakened spiritual/religious beliefs were rated lowest in importance (78%, 66%). Fourteen items were removed, two merged, and four reworded. The final questionnaire comprises 30 items with five sub-scales: Activity limitations and disruptions, Worry about cancer and the future, Self-esteem, Relationships, and Positive outlook and nine single items. Internal consistency was acceptable across sub-scales (Cronbach's alpha = 0.66–0.77).

Conclusion: The EORTC QLQ-AYA30 questionnaire was informed by the experiences of AYAs representative of different cancer and treatment types and intent, as well as different geographic regions across the world. This new cross-cultural measure provides a comprehensive, acceptable, and reliable assessment of QoL for this unique patient group across different cultures, for use in clinical practice, trials, and research.



◆ **Validity and acceptability of using an adult quality of life questionnaire, the EORTC QLQ-C30 for adolescents with cancer**

**Dr Samantha Sodergren**<sup>1</sup>, Dr David Riedl, Dr Jamal Hossain, Ms Haneen Abaza, Dr Amal Al-Omari, Dr Carlota Aguilera Ordoñez<sup>4</sup>, Dr Andrea Artigas Ramiro, Dr Chiara Besani, Dr Marta Campdepados, Dr Jacques van Heerden, Dr Lisa Lyngsie Hjalgrim, Dr Betty Illatopa, Dr Hiroto Ishiki, Dr Manjunath Nookala Krishnamurthy, Dr Lucas Moreno, Ms Rebecca Mottram, Prof Jelena Roganovic, Dr Anna Salo, Dr Caroline De Schepper, Dr Sophie Thomas, Dr Mark Tighe, Prof Anne-Sophie Darlington  
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Background: The EORTC QLQ-C30 (QLQ-C30) is the most widely used cancer-specific patient-reported outcome measure in adult clinical trials. However, its suitability for adolescents remains unclear given their distinct developmental needs. Assessing this could clarify whether adult findings are comparable to adolescents. Adolescents with cancer are often underrepresented in trials, and initiatives aim to improve their inclusion.

Aims: To determine the acceptability and validity of the QLQ-C30 for adolescents and explore their preferences for questionnaire delivery.

Methods: Adolescents aged 12–17 years with cancer on treatment, receiving palliative care, or recently completed treatment, completed the QLQ-C30 and the PedsQL Cancer Teen questionnaire. Interviews captured views on content and delivery format (paper vs electronic).

Results: Two hundred adolescents (mean age 14.5 years, SD = 1.6; 51.5% male) from 10 countries participated. Haematological cancers were most common (48%), followed by sarcomas (34%) and CNS tumours (8%); 91% had received chemotherapy. The QLQ-C30 took a mean of 12.1 minutes (SD = 9.0) to complete. Most described it as helpful, easy, and “not too boring.” Eight participants found a question upsetting or inappropriate; the financial difficulties item was most often deemed irrelevant (14%). A quarter suggested more age-appropriate content. Preferences: 58.5% favoured PedsQL, 29% QLQ-C30, and 12.5% had no preference. Paper completion (57%) was preferred over electronic. Psychometric analysis supported the QLQ-C30's subscale structure with acceptable to good internal consistency (Cronbach's alpha 0.70–0.84).

Conclusions: The QLQ-C30 shows potential as a valuable patient-reported outcome assessment for adolescents enrolled in clinical trials. This supports a life course measurement approach.



## Session 6: Digital and Technology Enhanced Care

### Lynch Choices: Development and implementation of a codesigned decision support intervention for inherited cancer risk management

**Prof Claire Foster**<sup>1</sup>, Dr Kelly Kohut<sup>2</sup>, Dr Kate Morton<sup>1</sup>, Lesley Turner<sup>1</sup>, Dr Rebecca Foster<sup>1</sup>, Prof Diana Eccles<sup>1</sup>, Dr Elizabeth Bancroft<sup>3</sup>, Prof Sir John Burn<sup>4</sup>, Prof Emma Crosbie<sup>5</sup>, Prof Mary Jane Esplen<sup>6</sup>, Dr Helen Hanson<sup>7</sup>, Dr Karen Hurley<sup>8</sup>, Dr Katie Snape<sup>2</sup>

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Background: Carriers of pathogenic germline variants associated with inherited cancer predisposition face difficult and socially complex decisions regarding risk management. Innovation is needed to scale up the delivery of personalised genetic cancer risk communication and decision support. Digital health interventions that support national guidance to embed genomic medicine and shared decision-making could empower patients to self-manage where appropriate to complement clinical interactions. Quality decision aids not only provide information but also encourage active deliberation and weighing up of personal priorities regarding difficult choices. Decision aids have been shown to improve knowledge and decrease decisional conflict.

Aims: To codesign a theory- and evidence-based patient-facing resource with patients and other experts - Lynch Choices. To present personalised cancer risk penetrance estimates via the Prospective Lynch Syndrome Database (PLSD) and UKCGG guidelines.

Methods: Decision aids were codesigned regarding taking daily aspirin and having gynaecological risk-reducing surgery, with interactive values-clarification exercises and a printable checklist to bring to clinic. Think-aloud interview and survey evaluation studies were completed to complement patient and public engagement activities to optimise Lynch Choices.

Results: Feedback from interviews (n=20 Lynch syndrome carriers) and survey responses (n=66) directed iterative optimisation of the prototype Lynch Choices decision aid. Refinements included clearer visual presentations of personalised genetic cancer risks and altered wording of the values-based exercises to make them more engaging and meaningful. Overall, carriers found the optimised decision aid helpful, easy to understand and would recommend it to others.

Conclusion: Lynch Choices was codesigned and evaluated by the people who will use it before clinical implementation. Research and engagement with the target population and expert partners resulted in important refinements for clearer, more engaging personalised genetic cancer risk communication and decision support. The approach aimed to avoid wasting precious healthcare resources and maximise potential for translation of research findings to patient benefit.



### ◆ Exploring supportive information for cancer survivors and professionals in Generative AI and social media: A structural topic modeling

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Background: Generative AI and social media have reformed the landscape of supportive information for cancer survivors and healthcare professionals. However, the nature and quality of this information across these distinct platforms are poorly understood.

Aims: This study employs structural topic modeling (STM) to examine the psychosocial supportive content on social media (WeChat, Rednote) and Generative AI chatbots (DeepSeek, ChatGPT).

**Methods:** We employed a qualitative design using STM to analyze supportive information from two social media platforms (n = 1177 posts, collected keywords: "cancer" and "psychosocial") and two Generative AI chatbots. GenAI data were generated using nine standardized prompts designed to elicit information for both survivors and professionals. STM was used to identify and compare topic prevalence, content, and temporal trends (for social media).

**Results:** STM revealed 5 topics from social media, dominated by caregiver reflections, family dynamics, and pediatric cancer care. The sharing of caregiving narratives emerged as a key trend for social support. In contrast, Generative AI topics (DeepSeek: 7; ChatGPT: 5) provided broader, synthesized overviews, commonly focusing on psychological distress, coping strategies, and healthcare professional practices. Social media offered personal, in-depth narratives (survivor and caregiver support), while Generative AI provided structured information (professional and survivor education). Notably, while DeepSeek offered critical reflections on care barriers, it also generated misinformation. Actionable help-seeking resources were limited across all platforms.

**Conclusions:** Findings emphasized the significance of information strategies in supportive care in cancer. Generative AI, particularly an AI Agent with RAG, should be fine-tuned or further trained with relevant data for effective practices. Cooperation between social media and key opinion leaders (KOLs) is an effective tool for promoting evidence-based information to the public. A hybrid model that integrates professional oversight, a Generative AI tool, and cloud platforms (for storing and analyzing data) is essential to ensure ethical compliance with psychosocial care.



## **Cancer Patients and Survivors' Perspectives on Artificial Intelligence-Powered Multimodal Analysis Tools for Emotional Distress Detection: A Qualitative Study**

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**Background:** Understanding whether novel technologies will be accepted and used by cancer patients is paramount for successful adoption. Artificial Intelligence-powered voice, speech semantics, and facial expression (AIVSFE) tools could be used to assess emotional distress. Current research lacks a nuanced view of how cancer patients and survivors perceive these tools.

**Aims:** To explore cancer patients and survivors' perspectives of AIVSFE tools based on the Unified Theory of Acceptance and Use of Technology (UTAUT) as a sensitizing framework.

**Methods:** We conducted a qualitative study using a constructivist paradigm and a Thematic Reflexive Experiential Analysis (TREA). 20 adult cancer patients and survivors were recruited irrespective of their illness situation or site. Semi-structured interviews were audio-recorded, transcribed verbatim, and analyzed to identify barriers and facilitators.

**Results:** Cancer patients and survivors' overall perceptions regarding AI are characterized by ambivalence, manifesting in feelings of inadequacy, lack of informed knowledge, and absence of control and understanding regarding its limits and applications. Concurrently, they express optimism regarding the potential of AI to enhance healthcare access, diagnostic capacity, and quality of life. Perceived facilitators were (1) the recommendation and supervision from a healthcare professional and endorsement of competent authorities, (2) immediate accessibility without delay and immediate responses, (3) neutral, human-free biases and accurate clinical memory, and (4) precise detection and support for early diagnosis. Barriers identified were (1) dehumanization and a deficiency in empathy, (2) mistrust of data vulnerability and undisclosed interests, and (3) inability to manage emotional subjectivity and provide tailored recommendations. Overall, most participants expressed their intention to use AIVSFE tools.

**Conclusion:** Cancer patients and survivors' perceptions of AIVSFE tools provide insights for prospective adoption in psycho-oncological settings. Incorporating the identified facilitators and barriers into

implementation strategies, including responsible and ethical AI policies, will help to ensure effective integration of AIVSFE tools into emotional distress assessments.



### **Exploring the acceptability and efficacy of a digital psychological intervention (Finding My Way-UK) for patients living with or beyond a sarcoma diagnosis**

**Lorraine Wright**<sup>1</sup>, Kieron King<sup>1</sup>, Nick Hulbert-Williams<sup>1</sup>

<sup>1</sup>Edge Hill University, Ormskirk, UK

**Background:** A diagnosis of sarcoma often brings psychological impacts such as distress and anxiety, and additional emotional problems linked to body image alterations. Finding My Way UK (FMW-UK) is a six-module, online psychological intervention, adapted from an Australian study and amended for the UK context. The intervention seeks to provide psychological support to assist well-being in cancer patients, in the case of this study, sarcoma patients.

**Aim:** This study aimed to explore the acceptability and efficacy of FMW-UK for patients living with or beyond a sarcoma diagnosis.

**Methods:** Participants were nine adults who had a previous sarcoma diagnosis. They were given access to the online intervention, and four to six weeks later, semi-structured interviews were conducted. A combined deductive and inductive framework analysis was undertaken using Gale et al. (2013) framework method in qualitative analysis.

**Results:** Engagement was moderately high, with only four participants completing all six modules. The four themes identified were: (i) Diagnosis and treatment experience; (ii) Content of intervention (acceptability); (iii) Content of Intervention (efficacy) including the sub-themes of (i) Retrospective opinion (ii) Relevance; and (iv) Usability of Intervention.

**Conclusion:** Participants highly valued access to the FMW intervention. Amendments were mainly related to suitability and content relevance, depending on where in the treatment trajectory an individual is. Namely, the further from active treatment and completion, the less relevant, although there were some exceptions. Participants valued the accessibility of the online intervention, appreciating the ability to complete modules in their own time and leave and return as needed. Overall, participants recognised that the intervention has an important role in supporting the mental health and well-being of people with sarcoma who often require timely support.



### **◆ Male cancer survivors and podcast advocacy: breaking borders through technology?**

**Dr Lydia Harkin**<sup>1</sup>, Dr Sarah Seymour-Smith<sup>1</sup>, Dr Eva Prikrylova<sup>1</sup>

<sup>1</sup>Nottingham Trent University, Nottingham, UK

**Background:** Men who have been diagnosed with cancer are often reluctant to engage with psychosocial support, stemming from traditional “stoic” expressions of masculinity. Despite this, some men can become active public advocates for example using online cancer outreach such as podcasts. Understanding how male cancer advocates overcome gendered barriers and adapt to cancer may help to widen support participation.

**Aims:** To understand how male cancer survivors use podcasts to talk about cancer advocacy.

**Methods:** We used a qualitative narrative approach to analysing podcasts produced by male cancer survivors. Podcasts were retrieved using freely available podcast platforms. Inclusion and exclusion criteria were applied. 24 podcasts were transcribed and analysed. Cancer sites included Prostate, Testicular, Colorectal, Lung, Sarcoma, and Leukaemia. Podcasts were produced in the UK, Canada, USA, and Australia. The average age of the podcasters was 35.7 (range=18-62 years).

Results: Analysis revealed that in the podcasts:

- i. Men foregrounded with their pre-cancer "Man-Card" identity e.g. roles as husband, career successes, or athleticism;
- ii. Cancer posed a "Loss of the Man-Card" where the men felt weakened by emotional and psychosexual concerns;
- iii. Men "Reassessed the Man-Card" when they grappled with the stigma of help-seeking;
- iv. The "Man-Card is Reclaimed" as the men reframed seeking help as a masculine show of strength, and advocacy as a positive form of male identity.

Conclusions: We capture how young men with cancer make advocacy acceptable by drawing on positive masculine concepts such as being present as a father, being strong for other men. Men may seek support earlier if we can address gendered barriers to support seeking. Freely available resources such as podcasts can be a valuable tool for men, but eHealth only breaks borders if it is accessible to all. We consider the applicability of our findings to a wider, diverse, global audience.



### **Using Innovative Technologies as part of an exercise programme to improve fatigue and quality of life in Children and Young People with Cancer: Experiences from the FORTEe Clinical Trial**

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Background and Aims: The FORTEe randomised controlled trial is exploring the effectiveness of a tailored exercise intervention in improving fatigue and quality of life in children and young adults with cancer (CAYA). In a sub-study, two technologies were used to support exercise: a motion-tracking device (Pixformance) for in-hospital training, and an augmented reality mobile application (AR app) for home-based exercise. These aimed to make physical activity more interactive and accessible. This study explored user experiences.

Methods: CAYA (4-21 years) and EHCPs from multiple European centres participated in the sub-study. The Pixformance device provided avatar-led exercise demonstrations and offered real-time feedback on movement quality during supervised training. The AR app delivered personalised exercise programmes, exercise demonstrations by a child-friendly avatar, and an integrated exercise diary. Semi-structured interviews with CAYA and anonymous online surveys completed by EHCPs explored user experiences.

Results: For the Pixformance device, 90 CAYA (mean age 11.1years) and 33 EHCPs provided feedback. CAYA described the device as novel and helpful, particularly for ward-based exercise. They appreciated the variety of exercises available and found the demonstrations helpful in enabling them to perform exercises correctly, though some technical issues limited usability. EHCPs reported benefits for supervised training but identified challenges related to transportability and offline functionality. For the AR app, 46 CAYA (mean age 13.6 years) and 31 EHCPs provided feedback. Both groups reported positive experiences, highlighting the novelty and engagement of AR demonstrations and value of personalised workouts. EHCPs reported the app should complement rather than replace face-to-face sessions. Suggested improvements for both technologies included gamification elements and avatar customisation.

Conclusion: Findings indicate both technologies were well-received by CAYA and EHCPs. Each offered distinct benefits for supervised and home-based exercise, highlighting their complementary roles in exercise programmes, hopefully contributing to improved outcomes for CAYA undergoing cancer treatment.

## Session 7: Interventions for Psychological Wellbeing

### ◆ Identifying comprehensive community-based cancer support programmes delivered in rural, remote and coastal communities: A scoping review

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**Background:** The UK population of people living with cancer is ≈3.5 million and is expected to increase to 5.3 million by 2040. Since 2014, numerous UK policies and strategies have supported the delivery of programmes to meet the wider psychosocial needs of people living with cancer. Evidence shows that community-based programmes delivered away from hospital settings are effective in supporting this population. People who reside in rural, remote and coastal areas face additional challenges accessing cancer care compared to urban counterparts.

**Aims:** To systematically synthesise the academic literature on comprehensive community-based cancer support programmes (which give access to multiple interventions to meet individuals' needs) in rural, remote and coastal settings.

**Methods:** The review adhered to the Joanna Briggs Institute methodology for scoping reviews and the PRISMA extension reporting checklist for scoping reviews. PubMed, Scopus, CINAHL, and Web of Science were searched in May 2025. Supplementary searching was conducted in Google Scholar and via reference lists of included studies. Data were charted and a narrative synthesis undertaken exploring key concepts and components of comprehensive community-based cancer support programmes in rural, remote and coastal areas.

**Results:** 17 studies were included (published 2010-2025) from Australia (n=3), Iceland (n=1), Ireland (n=2), USA (n=10), UK (n=1). Studies reported on various delivery models: structured time-limited programmes (n=6), non-time limited programmes (n=3), design of programmes (n=4), pilot programme (n=1), challenges to rehabilitation access (n=1), impact of Covid-19 (n=1), social work in accommodation for rural people undergoing treatment (n=1).

**Conclusion:** Analysis showed literature on a variety of delivery models for community-based cancer support programmes. Community-based support is essential in resource-limited areas where accessing formal cancer support can be challenging. Further research on the use of asset-based approaches to community-based support will have a positive impact on policy and practice in rural, remote and coastal areas.



### Psychosocial Interventions and Their Efficacy in Promoting Benefit Finding Among People Living with or Beyond Curatively Treated Cancer: A Systematic Review

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<sup>1</sup>Edge Hill University, UK, <sup>2</sup>Flinders University, Australia

**Background:** Psychosocial interventions can enhance adjustment after cancer, however evidence of their ability to facilitate positive psychological change remains inconsistent. Moreover, their specific effective components and mechanisms of change are poorly understood.

**Aims:** This review examined the efficacy of psychosocial interventions in promoting benefit finding and post-traumatic growth among adults living with and beyond curatively treated cancer, and identified shared mechanisms that may underlie efficacious approaches.

Methods: A systematic search of PsycINFO, Medline, CINAHL, Web of Science, and Scopus identified 47 eligible studies of psychosocial interventions for adults living with and beyond curatively treated cancer. Findings were narratively synthesised across five frameworks: cognitive-behavioural therapy-based, mindfulness-based, coaching/positive-psychology, meaning-centred, and psychoeducational support groups.

Results: Cognitive-behavioural therapy-based interventions demonstrated the most consistent efficacy, with 15 of 16 trials reporting significant post-intervention gains. Evidence for long-term maintenance was mixed across frameworks. Despite theoretical diversity, efficacious interventions appeared to converge on two trans-framework processes: metacognitive awareness, and the strengthening of self-management self-efficacy. These mechanisms may represent common pathways through which psychosocial interventions facilitate post-adversity growth.

Conclusions: Psychosocial interventions can reliably promote positive psychological change after curative cancer treatment. Their efficacy appears less dependent on framework than on the specific effective components shared across the interventions. Integrating these shared mechanisms may inform the design of future interventions that target positive psychological change, encompassing both benefit finding and post-traumatic growth.



### **Post-traumatic growth following treatment for sarcoma: is psychological flexibility a plausible intervention mechanism?**

**Prof Nick Hulbert-Williams**<sup>1</sup>, Dr Tim Cartwright<sup>1</sup>, Dr Lee Hulbert-Williams<sup>1</sup>, Dr Lesley Storey<sup>2</sup>, Prof Rachel Taylor<sup>3</sup>

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Background: Sarcomas are cancers which affect bone or connective tissue. They are comparatively rare, but affect people across the lifespan. Those diagnosed with sarcoma face high treatment burden, significant risk of metastasis and recurrence, and poor long-term outcomes, including higher psychological distress and fear of recurrence compared to other cancers. Psychological interventions could be helpful for this group, particularly if they can target positive psychology outcomes alongside distress reduction.

Aims: By undertaking a secondary analysis of existing data, we aimed to: (i) identify correlates of post-traumatic growth in sarcoma survivors, and (ii) explore whether therapeutic processes underpinning Acceptance and Commitment Therapy (ACT) might be plausible intervention targets.

Methods: We used an existing dataset of 229 UK participants who had been previously diagnosed with Sarcoma. The dataset was cross-sectional, and included a large battery of validated psychometric questionnaires assessing: socio-demographic profile, psychological distress, social support, quality of life, fear of recurrence, post-traumatic growth, and psychological flexibility.

Results: Sarcoma survivors who had a greater treatment burden (indicated by lower activity engagement and higher disability) are less likely to report post-traumatic growth. Post-traumatic growth was correlated with both fear of recurrence and quality of life, but not distress-related variables. Of the three ACT therapeutic processes, only the valued activities subscale significantly predicted post-traumatic growth outcomes.

Conclusion: We have identified which sarcoma survivors might most benefit from a post-traumatic growth focused psychological intervention. We also demonstrate that post-traumatic growth and psychological distress are poorly correlated, suggesting that distress-oriented and positive psychology interventions might offer parallel paths to better functioning. Values-based interventions seem the most plausible therapeutic processes to specifically target post-traumatic growth outcomes.



## Identifying Fear of Cancer Recurrence intervention targets amongst people living beyond cervical cancer

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**Background:** Cervical cancer (CC) typically affects younger women. The diagnosis is associated with a significantly reduced quality of life, and may include depression, anxiety, low self-esteem, social isolation, or worsening Fear of Cancer Recurrence (FCR) outcomes. There is a significant lack of research into FCR and targeted intervention development amongst this population despite the increased risk factors. This study aimed to address this gap.

**Aims:** To understand the experience of FCR in women who have undergone treatment for cervical cancer and to identify target areas for a tailored therapy intervention informed by CBT.

**Methods:** Women who had completed curative primary treatment for CC were invited to participate in an individual semi-structured interview. The topic guide was informed by CBT-based functional analysis targeting their thoughts, feeling and behaviours, exploring current psychological state, FCR, and resulting impact. Prior to the interview, participants received a narrative task and/or a Kawa model (river drawing) to stimulate thoughts about their experience with CC.

Interviews were transcribed by Microsoft Teams. Data was analysed with framework analysis, focusing on the most impacting factors of FCR amongst these participants. The findings were organised into antecedents, cognitive behavioural factors, and potential areas for intervention.

**Results:** To date, 12 women have participated in an interview. The median age was 44 years (range 35-57 years). Data-driven concepts included: avoidance, health anxiety, anticipatory loss, coping, and areas of support. Potential areas for intervention included: internal questioning of recovery (cognitive), HPV education (intervention), and a negative emotional response to the word 'cancer' (antecedent). The collated findings have been organised into these categories to form a cognitive behavioural basis for intervention development.

**Conclusions:** This study identified the need to address the concerning FCR outcomes in CC. Targetable areas of intervention were identified that can be used to develop a Cognitive Behavioural Therapy intervention framework.



## Session 9: Symptom Management

### ◆ Do brands matter? Insights from the SWITCH study on healthcare professionals' perceptions of oral SACT brand changes

**Rebecca Todd**<sup>1</sup>, Dr Zoe Moon<sup>1</sup>, Dr Pinkie Chambers<sup>1</sup>, Prof Robert Horne<sup>1</sup>

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**Introduction:** Adherence to oral systemic anti-cancer therapy (SACT) can be sub-optimal, and non-adherence, often driven by side effects, can worsen outcomes. Some patients report differences in tolerability between medication brands, which is often associated with reduced adherence and increased distress. Despite this, patient reports of brand-related side effects are often met with disbelief by healthcare professionals (HCPs), leaving patients feeling dismissed.

**Aims:** This study aimed to examine HCP perceptions and prescribing behaviours regarding oral SACT brand changes.

**Methods:** An online survey was developed, piloted, and distributed through UK oncology networks. Eligible respondents were HCPs with experience working in cancer care. The Qualtrics-hosted survey explored experiences and perceptions of oral SACT brand changes. Online focus groups were held with a subset of HCPs to further explore these themes.

**Results:** 180 responses were analysed (53% pharmacy, 30% nursing, 15% medical). Most respondents believed efficacy, side effects (SEs), and safety profiles were consistent between branded and generic medications and between different generics, though only 58% (N=77) believed different generics shared the same SEs. SEs were the most common patient-reported issue. However, nearly half of HCPs seldom granted patient requests for alternative brands, highlighting a potential barrier to addressing patient concerns. Reasons included cost, stock constraints, and uncertainty about whether symptom differences reflected actual medication differences or possible psychological influences. Focus groups reinforced survey findings, illustrating patient concerns about different brands and HCP decision-making complexities amid commissioning constraints and uncertainty about brand-related symptoms.

**Conclusions:** This study provides novel insights into how oral SACT brand switching is managed and highlights important opportunities to better support patients. While most HCPs viewed brands as equivalent, many patients report meaningful differences, particularly regarding side effects. Addressing this gap and strengthening clinical guidance on brand changes is essential to strengthen patient-provider trust, improve adherence, and support patient concerns.



### Training and Support Needs of Clinical Nurse Specialists in Blood Cancer Care: Findings from a UK Survey

**Rachael Simms-Moore**<sup>1</sup>, Dr Alison Llewellyn<sup>1</sup>, Prof Fiona Cramp<sup>1</sup>, Dr Karen Campbell<sup>1,2</sup>, Dr Julie Armoogum<sup>1</sup>

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**Background:** Clinical Nurse Specialists (CNSs) play a central role in supporting people living with blood cancer, providing continuity, personalised care, and expert clinical and psychosocial support. However, CNS development pathways and access to training and support vary considerably across services with implications for staff retention and service provision. Understanding current needs is essential to inform targeted workforce development.

**Aim:** To identify the training and support needs of CNSs working in blood cancer care across the UK, and to explore factors that enable or constrain access to professional development.

**Methods:** A cross-sectional online survey was distributed to CNSs working with blood cancer populations across the UK. The survey included questions on professional background, training access, perceived priorities

for onboarding and retention, and barriers and enablers to development. Descriptive statistics and content analysis of free text responses were used.

Results: Respondents (n=176), were predominantly experienced Band 7 CNSs (n=113) working full-time in specialist outpatient (n=97) and inpatient settings (n=87) with many also covering general hospital outpatient (n=74) and inpatient settings (n=65).

Communication skills and blood cancer-specific clinical knowledge were consistently ranked as the highest-priority training needs at onboarding and for CNS retention, followed by assessment, care planning, and core clinical skills. Workload pressures, limited backfill, and funding constraints were the main barriers to accessing and engaging with training, while managerial support, protected study time, and funding were key enablers. Charities were viewed as important partners in supporting and providing training and professional networking.

Conclusion: CNSs demonstrate strong motivation for continued development, but access is inconsistent and often dependent on local organisational support. Structured development pathways and protected learning time are needed to sustain and retain the CNS workforce in blood cancer care.



### ◆ Neurocognitive Sequelae of Chemotherapy: From Neural Network Dysfunctions to Post-Oncological Psychiatric Phenotypes

**Lidia G. Stoica**<sup>1,3</sup>, Mioara Grigoraş<sup>1</sup>, Lucian Ş. Burlea<sup>2</sup>, Anamaria Ciubară<sup>1</sup>

<sup>1</sup>"Dunarea de Jos" University of Galati, Galati, Romania, <sup>2</sup>Grigore T. Popa University of Medicine and Pharmacy of Iasi, Iasi, Romania, <sup>3</sup>Association Of Patients with Chronic Diseases Restart to Life, Bucharest, Romania

Background: Chemotherapy-related cognitive impairment ("chemobrain") represents a frequently underdiagnosed complication with major impact on the quality of life of cancer survivors. Although clinical manifestations—such as impairments in attention, working memory, and executive functions—are well described, the underlying neurobiological mechanisms and their relationship with psychiatric phenotypes remain areas requiring further clarification.

Objectives: This work aims to integrate recent findings from neuroimaging, neuroinflammation, and neuropsychiatry to explore how neural network dysfunctions, neurochemical alterations, and psychological factors contribute to the emergence and persistence of chemobrain.

Methods: A critical synthesis of literature from the past two decades was conducted, including functional studies (fMRI, PET), connectivity analyses, inflammatory biomarkers, and neuropsychiatric models. Emerging findings on the neuroinflammation–microglia–neuroplasticity axis are also discussed.

Results: Current evidence suggests consistent disruptions in the frontoparietal network, the default mode network, and executive circuits, which correlate with psychiatric symptoms such as anxiety, depression, fatigue, and emotional dysregulation. The overlap between these networks and circuits vulnerable to chemotherapy-induced neurotoxicity supports an integrative model of impairment characterized by significant interindividual variability.

Conclusions: Chemobrain should be conceptualized as a neurobiological condition with secondary psychiatric manifestations and complex biopsychosocial interactions. Understanding neural network dysfunctions provides opportunities for personalized interventions, early psychological monitoring, and integrated therapeutic strategies within oncological care.



## Session 10: Survivorship Care

**Right by You Wessex: a community outreach model of integrated personalised care for people living with and beyond cancer**

**Dr David Wright**<sup>1</sup>, Amanda Cummings<sup>2</sup>, Dr Rebecca Foster<sup>1</sup>, Prof Lynn Calman<sup>1</sup>, Jane Winter<sup>2</sup>, Prof Claire Foster<sup>1</sup>

<sup>1</sup>Centre for Psychosocial Research in Cancer, University of Southampton, UK, <sup>2</sup>Wessex Cancer Alliance, UK

**Background:** Improved diagnosis and treatment mean that cancer is increasingly viewed as a long-term condition. While this is to be celebrated, the long-term impact of living with and beyond cancer is significant. A shift to personalised care planning is required to support complex needs. However, poor integration across primary, community and secondary care can inhibit personalised care delivery.

**Aims:** Right by You Wessex aims to deliver an integrated approach to supporting people living with cancer across primary, community and secondary care, soon after diagnosis and throughout their cancer journey. An evaluation of the service assessed its effectiveness in identifying and supporting needs, and delivering integrated care.

**Methods:** The Right by You Wessex service involves a therapeutic dynamic and longitudinal Holistic Needs Assessment delivered by experienced Cancer Support Workers and Cancer Nurse Specialists trained in Acceptance and Commitment Therapy, conducted in a person's preferred location. Evaluation methods included 1. quantitative analysis of all service data, 2. 104 qualitative longitudinal interviews with people living with cancer; carers; secondary, primary and community care; specialist palliative care; commissioners, 3. documentary analysis, 4. cost analysis of service and cost savings to the NHS.

**Results:** The service was effective in enhancing patient experience and outcomes (e.g. identifying need), delivering integrated working between care sectors (e.g. improved communication), enhancing healthcare professional experience (e.g. building skills), and in improving health service delivery (e.g. reduced Emergency Department attendance). Right by You Wessex is resource intensive but generates potential cost savings through community management and averted admissions and referrals.

**Conclusion:** Right by You Wessex is an effective model of integrated personalised care, successfully identifying and supporting psychosocial and other patient-identified needs. It benefits health service delivery through upskilling the workforce and facilitating the management of cancer-related needs in the community. The service warrants consideration for replication in other regions.



**Promoting engagement in patient-initiated follow up and self-management behaviours: acceptability of the 'ACT now & check-it-out' intervention for Head and Neck Cancer (PETNECK2 study)**

**Dr Lauren Matheson**<sup>1</sup>, Prof Eila Watson<sup>1</sup>, Tessa Fulton-Lieuw<sup>2</sup>, Dr Saloni Mittal<sup>2</sup>, Piers Gaunt<sup>3</sup>, Ms Julia Sissons<sup>3</sup>, Dr Evaggelia Liaskou<sup>3</sup>, Claire Gaunt<sup>3</sup>, Dr Paul Nankivell<sup>2</sup>, Prof Hisham Mehanna<sup>2</sup>, Prof Jo Brett<sup>1</sup>

<sup>1</sup>Oxford Institute of Applied Health Research, Oxford Brookes University, UK, <sup>2</sup>Department of Cancer and Genomic Sciences, University of Birmingham, UK, <sup>3</sup>Cancer Research UK Clinical Trials Unit, University of Birmingham, UK

**Background:** Due to increasing incidence of Head and Neck Cancer (HNC) and overwhelming clinical demand on follow-up services, a new risk-stratified pathway, patient-initiated follow-up (PIFU) with an intervention support package is being evaluated in the PETNECK2 feasibility study. PIFU means that patients are responsible for initiating their cancer follow-up appointments.

**Aims:** To explore intervention acceptability to both HNC patients and health professionals, the perceived impact on self-management behaviours including self-surveillance and fear of cancer recurrence, and conduct intervention optimisation.

Methods: HNC patients were recruited from eight UK hospitals. All patients received the intervention support package following a clear PET-CT scan around one-year post HNC treatment. The intervention support package included a face-to-face education session with a health professional and a digital app and/or booklet, that aimed to support engagement in PIFU self-management behaviours (including regular checking for potential recurrence symptom changes; prompt help-seeking; self-management of fear of recurrence). Qualitative interviews were conducted with 25 patients who had been on PIFU for 1-2 months, and 7 health professionals from NHS Trusts involved in recruitment and/or intervention delivery. Thematic analysis was conducted, and themes were mapped to the COM-B model.

Results: The PET-CT guided PIFU intervention was found to be largely acceptable. Engagement in new habitual self-management behaviours was evident in most patients who reported having greater knowledge and confidence regarding these behaviours, provided by key elements of the intervention support package (e.g. demonstration of self-examination). Acceptability appeared lower in a few patients reporting low self-efficacy for self-examination, ongoing challenges with fear of recurrence and concerns over no scheduled appointments.

Conclusion: Our intervention support package ('ACT now and check-it-out') was largely acceptable and promoted patient engagement with key self-management behaviours required on PIFU. Findings can inform the design of future PIFU support packages. Following intervention optimisation, a UK-wide RCT is currently underway.



#### ◆ Examining the feasibility of using a routine needs assessment in the late effects clinic to improve support for survivors of a central nervous system tumour

**Dr Kate Law**<sup>1</sup>, Miss Ashleigh Ward<sup>1</sup>, Dr Sally Taylor<sup>1</sup>, Prof Martin McCabe<sup>1,2</sup>, Prof Janelle Yorke<sup>2,3</sup>

<sup>1</sup>The Christie Hospital NHS, Manchester, UK, <sup>2</sup>The University of Manchester, Manchester, UK, <sup>3</sup>Hong Kong Polytechnic University, Hung Hom, Hong Kong SAR China

Background: Young adult survivors of a central nervous system tumour can experience ongoing physical, emotional, cognitive and social issues, causing lower rates of employment, social isolation and lower quality-of-life compared to survivors of other cancers. The assessment of psychosocial needs is recommended in international guidance but there is no standard approach, creating inequalities in support.

Aim: To examine the feasibility of using a needs assessment tool designed with young adult survivors of a central nervous system tumour (YOU-CAN) in routine follow-up.

Methods: Eligible patients complete YOU-CAN via text link prior to their clinic appointment, results embed into the electronic health record to be discussed in consultation. Following clinic, participants are invited to complete an evaluation questionnaire or telephone interview to share their views on using/not using YOU-CAN. Clinician perspectives of using YOU-CAN will also be examined using interviews. Ethical approval was granted.

Results (preliminary): Since May 2025, 116 young people were approached to take part, 64 patients completed YOU-CAN and the evaluation questionnaire, 20 gave their reasons for not completing YOU-CAN, (5 declined the study, 27 questionnaires were posted, to be returned). There were no missing data in YOU-CAN responses. The number of needs reported by participants were: No needs (25%), 6-10 (27%), 1-5 (38%), all needs (4%).

YOU-CAN completion time and ease of completion were feasible. YOU-CAN improved communication, made them feel more involved in their care and allowed participants to discuss issues they would not have otherwise raised.

The most common reason for not completing YOU-CAN was not receiving the text link.

Conclusion: YOU-CAN provides a standard approach to assessing unmet needs. This study confirms the presence of unmet needs, demonstrates feasibility of routine assessment but highlights barriers. Future research will incorporate strategies to overcome barriers and inform equitable implementation. (We will present all data for the conference)



## **Progress with the SWEET Trial – Supporting women with breast cancer with adherence to adjuvant endocrine therapy**

**Dr Lucy McGeagh**<sup>1</sup>, Raegan Barrows<sup>2</sup>, Dr Sarah-Jane Stewart<sup>3</sup>, Prof Janet Dunn<sup>2</sup>, Prof Mary Wells<sup>4,5</sup>, Dr Guy Taylor<sup>6</sup>, Jan Rose<sup>7,8</sup>, Lesley Turner<sup>7</sup>, Dr Peter Donnelly<sup>9</sup>, Henry Cain<sup>10</sup>, Prof Andrew Wardley<sup>11</sup>, Prof Linda Sharp<sup>6</sup>, Prof Eila Watson<sup>1</sup>, The SWEET Research Team

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Background: Adherence to adjuvant Endocrine Therapy (AET) in women with early-stage breast cancer is a significant problem: approximately 20% have poor adherence after two years and around 50% by five years. The SWEET programme has developed an evidence-based, theoretically informed, patient-centred support intervention: HT&Me.

Aim: A large UK-wide randomised controlled trial (RCT) is underway to assess the effectiveness and cost-effectiveness of HT&Me in reducing poor adherence and improving quality of life (QoL).

Methods: This multi-centre, unblinded, pragmatic RCT compares HT&Me+ usual care with usual care alone. HT&Me comprises an initial and follow-up tailored consultation with a trained healthcare professional (HCP), access to an interactive web-app providing information, advice, support and behavioural strategies to support adherence, and monthly 'nudge' messages for 18 months. The target sample size was 1606, recruited over 24 months. Adherence is measured via self-report (MARS-5) at 6, 12 and 18 months and monthly community prescription encashment records. QoL is measured using FACT-G.

Results: We have recruited 1676 women from 66 UK NHS sites over 18 months. Sixty-one percent (40) of sites have delivered consultations through site staff; 39% (26) delivered them remotely via a trained Breast Cancer Now nurse. Withdrawals have been low (3%). To date, 78% (754/961) of women have completed 6-month questionnaires and 73% (243/334) 12-month questionnaires. Data quality is high, with self-reported AET adherence and HRQoL calculable for 99% of completed questionnaires. A mixed-methods process evaluation is underway. Initial qualitative feedback from women and HCPs is very positive. Interim web analytics show that most in the intervention arm have accessed the web-app (76.9% (574/746)), with 86.8% (249/287) still active at six months.

Conclusion: SWEET has successfully recruited to target. Follow-up is ongoing, and results will be reported in early 2028. An implementation workstream is preparing for rollout if the intervention proves effective and cost-effective.



## Poster Presentations

Listed alphabetically by presenting author surname

### The Impact of Financial Hardship on Quality of Life in Young Female Breast Cancer Survivors: A Longitudinal Analysis

Hong Chen<sup>1</sup>, Dr Rebecca Foster<sup>1</sup>, Dr Jamal Hossain<sup>1</sup>, Prof Lynn Calman<sup>1</sup>, **Prof Claire Foster**<sup>1</sup>

<sup>1</sup>University Of Southampton, UK

Background: Around 20% of breast cancer cases in the UK are in women under 50 and breast cancer is a leading cause of death in this group. Financial hardship has been recognised as a critical issue for breast cancer survivors; younger age is a risk factor for financial hardship. However, there are gaps in the current research literature with most studies using cross-sectional design. Longitudinal studies are essential to understand how financial hardship changes over time and impacts recovery.

Aims:

- Assess the longitudinal relationship between financial hardship and quality of life (QoL) in female breast cancer survivors under 50.
- Examine socio-economic factors which could impact financial hardship and how these affect QoL.
- Consider how healthcare providers could identify patients at risk of financial hardship and what supportive care strategies might enhance recovery.

Methods: Data from HORIZONS, a prospective cohort study which explored QoL in UK cancer survivors, was analysed. 1,189 female breast cancer patients, under 50, who received curative treatment and completed questionnaires at baseline, 3, 12, 18, 24, and 36 months were included. QoL was assessed using the Quality of Life in Adult Cancer Survivors scale. Financial hardship was measured by item 28 of the EORTC QLQ-C30 scale: 'Has your physical condition or medical treatment caused you financial difficulties?'. Linear Mixed Methods models were applied to explore the association between QoL and financial hardship over time alongside socioeconomic factors.

Results: Financial hardship was significantly associated with lower QoL at all time points. Participants who reported lower incomes and took more sick leave were also more likely to experience persistently reduced QoL.

Conclusion: Younger women experiencing financial hardship have worse QoL during breast cancer treatment and recovery than those who do not. Identifying financial hardship early and implementing supportive interventions to those affected will benefit this group.



### A Delphi Study To Understand Caregivers Experience of Cancer Healthcare Appointments

**Kavita Jassa**<sup>1</sup>, Dr Raluca Topciu<sup>1</sup>

<sup>1</sup>University of Exeter

Background: Cancer does not only affect the individual diagnosed but also impacts the lives of the individual's loved ones including, informal caregivers (IC). ICs play a vital role in supporting an individual physically, emotionally and psychologically. Understanding and improving the relationship between healthcare professionals (HCP) and ICs is essential to ensure the best care for the patient. Research has found that collaboration between HCP and ICs is not always productive, and that ICs often feel overlooked and not involved in the system supporting an individual.

Aims: To understand the experiences of ICs during cancer healthcare appointments. There are two research questions:

- What are the experiences ICs have of communicating with any oncology HCP in healthcare appointments?
- What challenges do ICs face in building a positive relationship with HCP?

Methods: A Delphi study was conducted for this research consisting of three rounds. Round one included a questionnaire with eight open ended questions sent to participants to gain their experience of healthcare appointments. Following content analysis, a Likert-scale questionnaire was created for rounds two and three which asked participants to rate their level of agreement on statements.

Preliminary results: Round one showed mixed experiences of healthcare appointments that led to four domains to consider in rounds two and three: inclusion, communication, emotional and psychological well-being, and organisation and practice. Mixed results were found in round two with some statements reaching consensus. Round three is currently with participants who are re-rating statements from round two with aggregated, anonymous responses of the other participants.

Conclusion: From the results so far, it is clear there are improvements that could be made to enhance the relationships between HCP and ICs including communication style, level of empathy and involvement of ICs in decisions. This research is expected to be completed by March 1st 2026.



### **Examining the correlation between patient and proxy reports of unmet needs using a needs assessment tool for adolescent and young adult survivors of a central nervous system tumour (YOU-CAN)**

**Dr Kate Law**<sup>1</sup>, Miss Ashleigh Ward<sup>1</sup>, Dr Sally Taylor<sup>1</sup>, Prof Martin McCabe<sup>1,2</sup>, Prof Janelle Yorke<sup>2,3</sup>  
<sup>1</sup>The Christie Hospital NHS, Manchester, UK, <sup>2</sup>The University of Manchester, Manchester, UK, <sup>3</sup>Hong Kong Polytechnic University, Hung Hom, Hong Kong SAR China

Introduction: YOU-CAN is a self-reported needs assessment tool, designed to identify needs deemed important by young survivors of a central nervous system tumour, who are known to experience lower quality of life compared to survivors of other cancer types. Proxy (any significant other) perceptions of unmet need are often informally acknowledged during consultation, particularly when the young person remains dependent on their support or where they lack awareness of their own limitations.

Aim: To examine the correlation between patient and proxy reports of unmet needs using YOU-CAN and better understand proxy perspectives of unmet needs.

Methods: Patients who complete YOU-CAN prior to their clinic appointment are invited to give a 'proxy YOU-CAN' to someone who knows them well (n=50). Responses to YOU-CAN are given on a Likert scale and the agreement between patient and proxy pairs will be examined and categorised according to: 1) a pair agreeing to presence/absence of need (i.e. agreement assumed where responses are in the same direction e.g. agree and strongly agree indicates agreement); 2) a pair specify the same strength of need (i.e. both participants report exact response on Likert scale). Further analysis will include correlation between the types of needs expressed.

Proxy participants are also invited to take part in a semi-structured interview (n=20).

Results (preliminary): To date, twenty participants completed 'proxy YOU-CAN'. The number of items patients and proxy agreed on were as follows: 11-16 (20%), 6-10 (60%), 1-5 (15%), 0 (5%). Items regarding social isolation and family planning were most likely to correlate, items about personal feelings showed least correlation.

Conclusion: Findings demonstrate divergence between young person and proxy reports of unmet need, supporting current evidence. This highlights a need to examine how we incorporate proxy perspectives of unmet needs in a standardised manner.

(We will report full results at the conference)



## Training in Psycho-Oncology: An Intern's Experience

**Maxine-Miles Leon Guerrero**<sup>1,2</sup>, Iain K. B. Twaddle<sup>1,2</sup>

<sup>1</sup>University Of Guam, Mangilao, United States, <sup>2</sup>Circle of Care Cancer Support and Psycho-Oncology Services, Hagatna, United States

**Background:** This poster presentation outlines the first author's experience as a psycho-oncology intern at a community-based cancer support program in the Pacific island of Guam called Circle of Care Cancer Support and Psycho-Oncology Services.

**Aims:** The internship was created to provide both undergraduate- and master's-level clinical psychology students with an opportunity to receive intensive training and clinical experience working with cancer patients and their families.

**Methods:** Interns are trained to co-facilitate cancer support groups, conduct individual and family counseling with cancer patients and their family members, assist with patient navigation, and help coordinate integrative oncology health and wellness services. They learn a plethora of innovative therapeutic activities focused on helping patients to cope with cancer and its treatment, while simultaneously providing support as patients face the psychological impact that comes with a cancer diagnosis.

**Results:** Internship outcomes are presented through narrative reflections from the first author, who recently completed a year-long internship with the Circle of Care program, highlighting the training she received, her clinical roles, her professional development, and her personal growth.

**Conclusion:** The internship provides a uniquely challenging, yet deeply rewarding clinical training experience. The central feature of the training program is that interns are tasked with providing psychological support to patients as they navigate their journeys facing a life-threatening illness. As a result, interns quickly come to form a bond with their clients that transcends the usual client-therapist relationship, allowing them to provide support on a deeper existential level. In addition to helping their clients manage their cancer, interns learn to help cancer patients and their families find meaning in some of the hardest moments of their lives.



## 'Accepting your Body after Cancer', a group-based online intervention for women treated for breast cancer: A feasibility randomised controlled trial

**Dr Helena Lewis-Smith**<sup>1</sup>, Dr Abigail Jones<sup>1</sup>, Prof Paul White<sup>1</sup>, Prof Sarah Byford<sup>2</sup>, Patricia Fairbrother<sup>3</sup>, Prof Shelley Potter<sup>4</sup>, Prof Diana Harcourt<sup>1</sup>

<sup>1</sup>University of the West of England, <sup>2</sup>King's College London, <sup>3</sup>Independent Cancer Patients' Voice, <sup>4</sup>University of Bristol

**Background:** Women treated for breast cancer often experience persistent body image concerns that affect wellbeing and quality of life. We developed 'Accepting your Body after Cancer (ABC)', a seven-session online group CBT-based intervention.

**Aims:** This study aimed to examine the feasibility of evaluating ABC in a randomised controlled trial. We aimed to recruit 120 women who had completed active breast cancer treatment and randomise them to ABC plus a psychoeducational body image booklet or to the booklet alone.

**Methods:** Participants were recruited across the UK via hospitals, cancer charities, and social media. ABC consisted of seven weekly two-hour online group sessions co-facilitated by a clinical psychologist and a cancer support specialist. The programme targeted unhelpful thoughts, self-criticism, and avoidance, and incorporated body functionality, media literacy, and self-compassion. Feasibility outcomes included recruitment, retention, and completion of measures at baseline and 1-week, 3-month, and 6-month follow-ups. Acceptability was assessed through questionnaires and interviews. Proposed primary outcomes were the Kessler Distress Scale (K10), Body Appreciation Scale (BAS), and FACT-B: Breast Cancer Subscale, with secondary outcomes including the Body Image Scale (BIS) and BREAST-Q: Sexual Wellbeing Scale. Health

economic measures included the Adult Service Use Schedule (ADSUS), EQ-5D-5L, Recovering Quality of Life-Utility Index-10 (ReQoL), and Work and Social Adjustment Scale (WSAS).

Results: The recruitment target (N=120; Mage = 51.2) was met, with 83.3% retention and no differences in drop-out or outcome completion between groups. Sixty percent of intervention participants attended at least six sessions, reporting high satisfaction (M= 4.2/5). Qualitative feedback highlighted increased self-acceptance, shared strength, and practical tools. Participants rated the research experience positively (M=3.9/5). Analyses favoured ABC on the BAS, BIS, FACT-B, WSAS, and ReQoL, with significant between-group differences indicated up to 6 months follow-up.

Conclusion: ABC is feasible, acceptable, with shows promising early benefits, supporting progression to a fully powered trial.



## **Development of a therapeutic creative writing program for cancer patients**

**Camille Maestrecampo**<sup>1,2</sup>, Iain K. B. Twaddle<sup>1,2</sup>

<sup>1</sup>University of Guam, Mangilao, United States, <sup>2</sup>Circle of Care Cancer Support and Psycho-Oncology Services, Hagatna, United States

Background: Receiving a cancer diagnosis can be a daunting and sometimes dehumanizing experience. Following a series of anxiety-provoking tests, scans, and biopsies, a diagnosis of cancer can quickly come to define an individual's sense of self and identity. As cancer is often believed to be an incurable disease associated with death, identification with cancer can quickly undermine one's sense of peace and contentment, leaving cancer patients feeling that they are no longer in control of their lives.

Aims: To counter the dehumanizing aspects of cancer and empower patients to rediscover their sense of agency, the authors are developing a creative writing program for cancer patients in the Pacific island of Guam called "The Language of Healing." As Pacific island cultures have a rich tradition of story telling, creative writing can serve as a culturally responsive avenue for patients to confront and explore their experiences, articulate what is meaningful to them, and reimagine their lives beyond illness.

Methods: In 2025, a preliminary creative writing workshop was held for cancer patients to engage in expressive writing, reflection, and group sharing as therapeutic tools for emotional healing and understanding.

Results: Observations from the initial workshop suggest that participants experienced increased emotional clarity, improved self-understanding, and a stronger sense of community and resilience. Thus, the authors plan to implement a monthly creative writing workshop for Guam's cancer community.

Conclusion: Creative writing offers a powerful way for cancer patients to reconnect with a deeper sense of self characterized by wisdom, clarity, and peace. Through writing, individuals can confront and explore life, determine what is important and meaningful, make choices about how they wish to live, and rediscover the person they want to become. In short, creative writing can be a transformative therapeutic intervention, one that serves as both a mirror and a means of healing.



## **Photofantasy as an Arts-Based Method for Exploring Cancer Experiences: Insights from Jo Spence and Participatory Workshops**

**Dr Lizzie Merrill**<sup>1</sup>

<sup>1</sup>University Of Surrey, Guildford, UK

Background: Angela Woods argues that modes of expression beyond verbal narrative are crucial for revealing deeper representations of lived experience (Woods, 2011). Jo Spence's artistic practice of photofantasy, developed during her experience with leukaemia, offers a compelling example. When illness made her previous photographic methods inaccessible, Spence began collaging images from her personal archive to

construct entirely new scenes. This unique practice enabled her to navigate illness and reclaim agency over her narrative. This study explores photofantasy as a creative tool for articulating cancer experiences beyond conventional clinical accounts.

**Aims:** To establish photofantasy as a powerful tool for self-expression and empowerment for people navigating the complexities of cancer.

**Methods:** Building on Spence's work, five women aged 36–77 with diverse cancer diagnoses participated in one-to-one photofantasy workshops. Sessions involved creating collages from personal photographs, medical scans, and found imagery, accompanied by reflective discussion. Artworks and transcripts were thematically analysed.

**Results:** Participants produced 32 artworks and rich narratives. Themes included:

- The collage-maker as surgeon, whereby cutting and assembling images became a metaphor for reclaiming agency over treatment and surgical encounters.
- Liquid metaphors for time, which involved visualising liquids of different viscosities to describe the altered temporalities of illness.
- Hybrid bodies, in which participants represented their own fragmented, technologized bodies post-treatment.

Photofantasy facilitated emotional expression, challenged biomedical reductionism, and offered a creative space for negotiating identity.

**Conclusion:** Photofantasy is a unique arts-based intervention. It enables patients to reconfigure medical imagery, articulate complex experiences, and assert control over representation. Future research should explore its therapeutic potential in group and clinical settings.



## **Inequalities in cancer treatment in the UK: A scoping review**

**Tetyana Perchyk**<sup>1</sup>, Elizabeth Merrill<sup>1</sup>, Natalie Gil<sup>1</sup>, Gary Abel<sup>2</sup>, Eva Morris<sup>3</sup>, Emma Giles<sup>4</sup>, Elena Finn<sup>5</sup>, Katie Spencer<sup>6</sup>, Kate Brain<sup>7</sup>, Jenny Harris<sup>1</sup>, Katriina Whitaker<sup>1</sup>, Robert Kerrison<sup>1</sup>

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**Background:** Inequalities in cancer treatment exist across a range of cancer types, demographics and geographical contexts. These disparities contribute to differences in cancer survival. A clearer understanding of these inequalities is needed to support targeted interventions and ensure appropriate support is provided throughout the cancer pathway.

**Aims:** This review aimed to:

- Identify UK studies exploring inequalities in cancer treatment;
- Establish an evidence base of known inequalities to inform research and practice.

**Methods:** Following the five-stage Arksey and O'Malley framework, we conducted a scoping review of UK-based studies investigating inequalities in cancer treatment. A comprehensive search strategy was developed using the PCC mnemonic, Population (adults with cancer), Concept (treatment receipt/delay/adherence), and Context (UK), incorporating >130 key words and MESH terms, and was applied to Web of Science, Embase, Medline, CINAHL and Google Scholar. Results were exported to Rayyan AI for duplicate removal and screening. Articles published >2011, available in English, including UK adults treated for cancer, and using epidemiological designs, were eligible. Papers were excluded if they included individuals <18 years of age or only explored non-curative treatments. An initial sample of 350 papers was reviewed by four authors, with remaining titles and abstracts then divided equally among them for title/abstract review. Results are reported in accordance with the PRISMA Extension for Scoping Reviews (PRISMA-ScR).

Results: We identified 5,110 unique articles. Of these, 217 were eligible for full text review. Preliminary findings indicate that most papers examined inequalities in age, sex or ethnicity, with fewer exploring other population groups.

Conclusion: Further research is needed to determine whether specific populations, such as people with a learning disability, autism and/or severe mental illness, experience treatment inequalities. These groups face poorer cancer survival and evidence from other areas of cancer care suggest they may have additional psychosocial needs requiring reasonable adjustments.



### **RAD-PIT: Co-design of a research protocol for the use of Macimorelin as a diagnostic test for growth hormone deficiency in patients undergoing proton and photon radiotherapy**

**Melissa Perry**<sup>1</sup>, Dr Fernando Osorio<sup>2</sup>, Ben Garlick<sup>3</sup>, Emily Weaver-Holding<sup>4</sup>, Dr Robert D Murray<sup>5,6</sup>, Prof Catherine McBain<sup>1,7</sup>, Prof David Thomson<sup>1,7</sup>, Dr Glen P Martin<sup>7</sup>, Dr Lillian R Chen<sup>1</sup>, Dr Sally Taylor<sup>1,7</sup>, Dr Claire E Higham<sup>1,7</sup>

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Background: Increasing evidence indicates co-designing research protocols with patient and public involvement and engagement (PPIE) members and industry enhances acceptability, feasibility, and engagement of new diagnostic tests. However, there are currently no UK protocol co-design guidelines.

Aims: Involving multiple stakeholders as equal partners in the co-design of guidelines and a research protocol exploring a new diagnostic test for growth hormone deficiency (Macimorelin) for teenagers and adults who have received proton/photon radiotherapy for brain or head and neck tumours.

Methods: A study team was established involving multiple stakeholders: Not-for-profit PPIE experts/recruiters (Vocal), 17 PPIE contributors, two project leads, a pharmaceutical representative, statistician, and three clinicians. The project comprised three work packages (WP):

- WP1: in-person scoping exercise with 15 PPIE contributors to understand the barriers/opportunities of collaborating.
- WP2: in-person exploratory event with 10 PPIE contributors to investigate the feasibility/acceptability of Macimorelin.
- WP3: five flexible online meetings with two public advisors, tailored to clinician expertise, to co-design the study protocol.
- Stakeholder feedback about the process was collected.

Results:

WP1: 'Working-Together Guidelines' were created based on eight key principles: trust, honesty, communication, unity, respect, inclusivity, learning, and support. The guidelines ensured open, respectful and supportive communication throughout the project.

WP2: contributors shared protocol preferences, information needs and reservations, resulting in the conceptualisation of a potential protocol.

WP3: a complete protocol and inclusive patient information sheets were created. All stakeholders provided positive feedback.

Conclusions: Key lessons were to step out of the traditional comfort zone. Early and continuous collaboration with stakeholders can shape research in meaningful ways, enhancing its quality, relevance, and impact. Mitigating potential barriers is important; explaining complex terminology and holding separate age-appropriate sessions can reduce power imbalances and increase accessibility and contribution confidence. Future funding plans include collaborative systematic reviews, publishing the novel co-design process, and protocol submission.



## **Incorporating Public and Patient Involvement in Research to Investigate the Experiences and Support Needs of Acute Oncology Patients**

**Amy Poole**<sup>1</sup>, Dr Lucy McGeagh<sup>1</sup>, Dr Kay McCallum<sup>1,2</sup>, Prof Eila Watson<sup>1</sup>

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**Background:** NHS priorities emphasise incorporating patient and staff voices in service improvements and research, and there is support for autonomy over participation, even near the end of life.

**Aims:** As part of a larger body of work, our study involves interviewing a diverse sample of 20-30 Acute Oncology (AO) patients to enhance our understanding of their experiences and support needs. Patient and Public Involvement (PPI) informed the study design.

**Method:** The PPI opportunity was advertised via Cancer Research UK. Twenty-three people expressed interest in taking part. Six women and two men were recruited, with AO experiences including treatment side effects, metastatic cord compression, and diagnosis during emergency presentation, occurring between ~6 months and 6 years prior. The group was split into two focus groups, held via Zoom, to discuss the study design and ethical considerations.

**Results:** All eight PPI members were keen to participate in this type of study, perceiving a real need for research into AO experiences, with one member stating, "You need to hear [these stories], because everyone meant well, but it didn't always work."

Some members felt ready to talk about their experiences quite soon afterwards, while others needed much longer to process what had happened. Members were open to recruitment via their direct care team, charities and support groups, and welcomed in-person, online or poster-based approaches.

A member with a rare cancer type perceived a relative lack of participation opportunities and was pleased to see all cancers included. The group appreciated efforts to improve inclusivity, such as the option for verbal consent.

**Conclusion:** PPI members were keen to be made aware of research opportunities, make their own choices about if and when the time is right, and could see great value in participating, supporting future sensitive research into AO experiences.



## **Navigating parenthood while coping with cancer in the Pacific island of Guam**

**Jeanine Quinto**<sup>1,2</sup>, Iain K. B. Twaddle<sup>1,2</sup>

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**Background:** A cancer diagnosis can profoundly impact a person's life, necessitating significant lifestyle changes to accommodate treatment and recovery. In their efforts to survive cancer, patients often become deeply involved in the treatment process, followed by ongoing health monitoring and fear of recurrence. Yet, while patients are entrenched in their cancer journey, they continue to fulfill multiple roles integral to their identity and daily life. For cancer patients with children, navigating the complexities of parenthood while confronting a cancer diagnosis can be overwhelming, leaving them feeling inadequate in their parental role.

**Aims:** This poster outlines a framework for providing psycho-oncology care to cancer patients with children in the Pacific island of Guam through a community-based program called Circle of Care Cancer Support and Psycho-Oncology Services. As family roles are central to Pacific island identities, successful psycho-oncology interventions for parents diagnosed with cancer in Guam should recognize parenthood as a critical component of their cancer journey.

**Methods:** While Circle of Care offers a wide range of services—from cancer support groups and patient navigation to community engagement and integrative health and wellness activities—our primary intervention

for helping participants to balance parenthood and being a cancer patient is individual and family psycho-oncology counseling.

Results: Outcomes have been striking—100% of program participants with minor children have requested both individual counseling focused on parenting and family counseling focused on improving their relationships with their children. Conclusion: Individual and family psycho-oncology counseling can help cancer patients with children to rediscover their parenting role. Not only does this strengthen their relationships with their children and improve family dynamics, it also gives parents with cancer reassurance that they can continue to play a vital role in the lives of their children despite the significant challenges they face as cancer patients.



### **Specialist Psycho-Oncology Involvement in the Manchester Model Digital Clinical Placement: the Impact on Student Development**

Jo Qurashi<sup>1</sup>, Anne Crook<sup>1</sup>, Alison Sanneh<sup>1</sup>, Hanna Simpson<sup>1</sup>

<sup>1</sup>The Christie NHS Foundation Trust

Background: Psychological distress is common across the cancer pathway and significantly affects patient experience and outcomes. Student nurses often have limited exposure to psycho-oncology in traditional clinical placements. We aimed to address this gap by introducing a dedicated psycho-oncology session led by two specialist psycho-oncology clinicians into the online Manchester model digital clinical placement (DCP) in Oncology.

Aims: To explore how a psycho-oncology session within an online DCP affects nursing students' understanding of the importance of psychological care.

Methods: 12 DCP cohorts comprising of 1,617 mixed-field nursing students from six Universities took part in psycho-oncology sessions. The DCP was designed with a strong focus on psychological awareness, empathetic communication, and holistic care, and breakout rooms were opportunities for sharing experiences and teamworking. Students kept written reflections after each session following Driscoll's reflective model, and psycho-oncology reflections were thematically analysed using AI. Themes generated were tested for accuracy by an educationalist.

Results: Key themes identified were:

- A deeper understanding of how psychological factors shape cancer experiences.
- Improved confidence in talking to patients experiencing distress or uncertainty.
- Increased ability to signpost or refer patients to appropriate support services.
- Recognition of how psychological wellbeing influences treatment engagement, adherence, and recovery.
- A commitment to embedding active listening, empathy, and holistic assessment into their future practice.
- Appreciation for the psychological needs of families as well as patients.
- A greater understanding of the importance of multidisciplinary collaboration in supporting patient wellbeing.

Conclusion: The inclusion of a dedicated psycho-oncology session into a high quality DCP demonstrates an effective and sustainable approach to enhance the future nursing workforces' understanding of psychological care in oncology.



## Responding to cancer patients who refuse treatment: The role of psycho-oncology

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**Background:** Responding to cancer patients who refuse treatment requires navigating the complexities of shared decision making, a challenging process whereby clinicians must demonstrate compassion and respect for patient preferences while also helping patients to fully understand the treatment options available to them.

**Aims:** This poster outlines the development of a psycho-oncology protocol for responding to cancer patients who refuse treatment in the Pacific island of Guam.

**Methods:** When working with cancer patients who refuse treatment, the authors follow an 8-step procedure: (1) establish trust and rapport to create a strong therapeutic relationship; (2) examine patient misunderstandings regarding their diagnosis and treatment options; (3) explore any personal, cultural, and religious belief systems held by the patient that conflict with biomedical frameworks; (4) outline treatment options in a way that is easy to understand; (5) set up meaningful opportunities for patients to access treatment services, including introducing them to oncologists at cancer support group sessions; (6) connect patients with others who have completed treatment for a similar type of cancer; (7) help patients think through the information provided by medical specialists and other cancer patients so they can make wise decisions regarding their treatment; and (8) provide mental health care to help patients overcome fear and anxiety, and to build the confidence and strength needed to face their cancer treatment.

**Results:** Implementation of the steps outlined above has led some patients to reconsider their initial decision to refuse treatment, however, development of the protocol is still in its early stages.

**Conclusion:** Due to their expertise in addressing the anxiety, fear, and depression that often arise when patients receive a cancer diagnosis, psycho-oncologists are in a unique position to help guide patients who either refuse treatment or are overwhelmed by cancer treatment decisions.



## Evaluating the Pilot of Penny Brohn UK's Preparation-for-Treatment Support Service to Enhance Patient Activation in Cancer Prehabilitation

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**Background:** Prehabilitation supports people with cancer to prepare physically, psychologically, and emotionally for their treatment, with evidence suggesting benefits to recovery, tolerance of treatment, and quality of life. Penny Brohn UK and NHS oncology teams in the BNSSG ICB have co-developed and are piloting an integrated preparation-for-treatment service to expand availability and align voluntary-sector and NHS resources.

**Aims:** The aim of this evaluation is to assess whether participation in the Penny Brohn UK Preparation for Treatment support pilot service leads to any improvements in patient activation, measured by the Patient Activation Measure (PAM) tool.

**Methods:** This prospective study will recruit adults ( $\geq 18$  years) with a new cancer diagnosis who have not yet started active treatment. Participants will complete a 2–6-week online preparation-for-treatment programme consisting of personalised support in nutrition, physical activity, emotional wellbeing, and behaviour change. Data will include PAM scores collected at baseline and at discharge (2–6 weeks post-enrolment), plus demographic and cancer type and cancer status. Quantitative analysis will explore changes in PAM scores and stratify by participant demographics and clinical status.

**Results:** Improvement in PAM scores would indicate that people have better knowledge, skills and confidence to manage their health. This is an evaluation of a pilot, and there is no control group, but results

would show if improvement in activation is occurring for this group receiving support and indicate that the pilot is performing appropriately, requiring further investigation. Pilot study outcomes pending by February 2026.

Conclusion: This study will address a key gap in UK prehabilitation provision by evaluating a cross-sector, co-designed pilot model aiming to improve patient activation ahead of cancer treatment. Findings will inform feasibility, scalability, and future developments of this fledgling service for Penny Brohn UK.



## **The Effectiveness of Virtual Reality Interventions within Specialist Palliative Care (VR-SPC): A Hermeneutic Single Case Efficacy Design (HSCED) Series**

**Alice Shaw**<sup>1</sup>

<sup>1</sup>University Of Lincoln

Background: Individuals receiving specialist palliative care, as well as their relatives or carers, are at risk from developing mental health difficulties. Palliative care is about providing holistic support and prioritising individuality, therefore interventions which lend themselves to encompass choice and personalisation are vital. Virtual Reality (VR) interventions may show promise for this, as they have been found a VR to reduce symptom burden and alleviate distress for individuals in palliative care contexts, however further study about the effectiveness as well as mechanisms of change of VR is required.

Aims: This study aims to explore the effectiveness of VR interventions for achieving personally important goals. Participants are those receiving specialist palliative care as a patient on either an inpatient or outpatient basis. Where applicable, the study also aims to explore the experiences of palliative care patients and their relatives or partner (participant companions) via joint VR interventions if participants opt for this.

Methods: This study adopts a mixed-methods, Hermeneutic Single Case Efficacy Design Series (HSCED) to investigate the effectiveness of VR interventions. Up to 3 VR sessions are offered to participants. The focus of the intervention will be based on participant determined goals for VR use e.g., bucket list activities, relaxation, making new memories. Questionnaire data is collected pre and post VR sessions to measure wellbeing. Participants are then invited to a change interview, analysed via thematic analysis. Findings will be organised and shared with an expert adjudication panel to assess whether VR is effective or not for reaching personally important goals.

Results & Conclusion: Currently the study is ongoing but preliminary findings would be available by the time of the conference in March 2026. So far, VR has been helpful for participants to work towards reaching their personally important goals.

Reflections of VR interventions would also be offered.



## **Childhood, adolescent and young adult cancer and the prevalence of diagnosed autism or attention deficit hyperactivity disorder: A systematic review and meta-analysis**

**Dr Hannah Slevin**<sup>1,2</sup>, Dr Fatmaelzahraa Awadalla<sup>2</sup>, Prof Richard G Feltbower<sup>3</sup>, Dr Louise Robinson<sup>1,4,5</sup>, Prof John-Paul Kilday<sup>1,4</sup>, Prof Bob Phillips<sup>6,7</sup>, Dr Shruti Garg<sup>2,4</sup>, Prof Martin G McCabe<sup>1,5</sup>

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Background: Attentional and social differences are common in children, teenagers and young adults (CTYA) impacted by cancer. However, the likelihood of co-occurring neurodevelopmental conditions, such as autism and attention deficit hyperactivity disorder (ADHD), remains unclear.

**Aims:** This systematic review and meta-analysis examined the prevalence of autism and ADHD in CTYA affected by cancer or benign brain tumours.

**Methods:** The review was reported according to PRISMA guidelines. Studies were exported from databases up to April 2025. Those reporting on CTYA from birth to 39 years at the time of cancer diagnosis, and a diagnosis of autism or ADHD at any age, were eligible for inclusion. Following narrative review, random-effects meta-analyses calculated the overall prevalence of autism and ADHD. The JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data identified higher quality studies for sensitivity analyses.

**Results:** Of the 34 studies eligible for inclusion in the review, 25 contributed to the meta-analyses. ADHD prevalence in CTYA with cancer was 8.91% (6.32-12.43%), increasing to 8.99% (5.70-13.91%) on sensitivity analysis. ADHD prevalence in those with CNS tumours was 9.61% (6.44-14.12%). Autism prevalence was 1.52% (0.72-3.20%), reducing to 1.32% (0.56-3.09%) on sensitivity analysis. Autism prevalence in those with CNS tumours was 3.56% (2.16-5.83%). Cancer type contributed to between-study heterogeneity. The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) strength of evidence was 'low', increasing to 'moderate' for the sensitivity analyses.

**Conclusions:** Summary estimates indicate a higher prevalence of ADHD in CTYA with cancer, and of autism in those with CNS tumours, compared to the general population. Limitations of the review include inclusion of English-language studies only. Timely recognition of autism and ADHD in this population is important to optimise social, educational and health outcomes.

Systematic review registration: PROSPERO registration number CRD42025644175  
<https://www.crd.york.ac.uk/PROSPERO/view/CRD42025644175>



## **A National Living Laboratory for Teenage and Young Adult-Onset Cancer**

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**Background:** Teenagers and Young Adults (TYAs, 16-24 years) living with and beyond cancer experience a large number of life disruptions due to their diagnosis. Traditional research and service design approaches are under-representative of their needs and sometimes fail to meet them where they are.

**Aims:** We are developing a National TYA Living Laboratory - an open innovation and participatory infrastructure designed to encourage and empower continuous support and co-design of care and resources between TYAs and professionals.

**Methods:** This project has two aims: 1) to develop an infrastructure for ongoing communication and co-design; and 2) consider social integration and support projects within the infrastructure. It serves as a proof-of-concept to test the feasibility and acceptability of a digitally-enabled continuous engagement environment that combines asynchronous discussions and periodic workshops. Young people will co-identify and prioritise key barriers and enablers of social integration, co-define 'successful return' to social engagement, and co-develop interventions and service innovations.

**Results:** The evaluation will include feasibility (use, participation), acceptability (satisfaction, empowerment), and impact (relevance, knowledge exchange), and sustainability.

**Conclusions:** The National TYA Living Lab is a collaborative initiative between the Open University, University of Leeds, and The Children & Young People's Cancer Association where the infrastructure will be based. It aims to advance equitable, sustainable and innovative engagement in TYA research and service. The first project will establish the basic processes and infrastructure for subsequent projects defined by TYAs themselves and is currently open to additional stakeholders.

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## Overcoming cancer treatment barriers through patient navigation and advocacy services in the Pacific island of Guam

**Iain Twaddle**<sup>1,2</sup>, Jeanine Quinto<sup>1,2</sup>, Maree Saloma<sup>1,2</sup>

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**Background:** Due to its remote location in the Western Pacific Ocean, the island of Guam has a significant shortage of oncology services. While chemotherapy, radiation, and surgery are available, it is challenging to recruit medical oncologists, radiation oncologists, and other cancer specialists to serve the island community. As a result, cancer patients, particularly those diagnosed with rare and complicated cancers, are often referred to off-island medical centers in Hawai'i, the US mainland, the Philippines, and other nearby Asian nations.

**Aims:** This poster outlines the role of personalized patient navigation and advocacy services provided by a community-based psycho-oncology program to help cancer patients access oncology specialists off island when they are not able to obtain the treatment they need on Guam.

**Methods:** Cancer patients on Guam encounter multiple treatment barriers: (1) limited cancer specialists on island; (2) inadequate referral procedures for off-island cancer care; (3) referrals not accepted at off-island medical centers; (4) high cost of off-island treatment for patients without health insurance; and (5) high cost of travel and accommodations for off-island medical care. To overcome these challenges, the authors established an off-island referral protocol including: (1) locating appropriate and affordable oncology specialists; (2) advocating for patients by speaking directly with the specialist prior to making referrals; and (3) providing psychological support to patients and their families throughout the referral process.

**Results:** Some patients have been successfully referred for off-island medical care, while others have had their case denied with no explanation. One approach that has worked particularly well is connecting patients with an off-island specialist who can guide their treatment on Guam through telehealth.

**Conclusion:** The significant challenges associated with accessing cancer care in remote locations demonstrate the importance of personalized patient-navigation and advocacy services to ensure that patients receive the life-saving treatment they need.

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## Patient Experience Sub-study of a Randomised UK Multicentre Phase 2 Trial of ASTX727 versus Hydroxycarbamide/Best Supportive Care in Myelodysplastic Syndrome (MDS)/Myeloproliferative Neoplasm (MPN) Overlap Syndromes (AMMO)

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**Background:** Myelodysplastic syndrome/Myeloproliferative neoplasm (MDS/MPN) overlap syndromes are haematological malignancies with intersecting features of myeloid dysplasia and proliferation, most prevalent in older male adults. Due to concurrent comorbidities in this population, clinical trials can be challenging to design and deliver. AMMO is a UK randomised phase 2 trial comparing the oral hypomethylating drug ASTX727 versus Hydroxycarbamide/Best Supportive Care (HC/BSC).

**Aims:** Evaluate patients' trial experience to establish support needs, identify participation barriers and inform future trial modifications.

Methods: Nested qualitative sub-study. Consenting patients participated in longitudinal semi-structured interviews at trial entry, end of cycle 6 (C6) and 12months. Reflective thematic analysis was performed independently by two researchers. Content analysis compared prevalence and burden of symptoms and side effects (SEs).

Results: Forty-four patients participated in the sub-study (ASTX727 arm=32; HC/BSC arm=10; screen fails=2). Nine participants completed interviews at three time points, 17 completed two interviews and 18 completed one. Time points were: trial entry (n=23); C6 (n=34); 12months (n=22), 79 in total.

The analysis is situated within the four domains of the McCormack and McCance Person-Centred Care framework.

1. Prerequisite: Staff were considered professionally competent, displaying skills needed to communicate/support effectively and accommodate individual needs.
2. Care environment: Patients were satisfied with trial team's support, particularly proactive SE management.
3. Person-centred processes: Appropriate information was mostly delivered to support decision-making. Many expressed anxieties initially regarding randomisation. Those randomised to HC/BSC expressed disappointment/upset but recognised its importance to trial design.
4. Person-centred outcomes: Some participants felt explanations (and proposed next steps) when approaching end of trial (C6) were insufficient. Although most were satisfied with information provision, some highlighted suboptimal areas.

Conclusion: Overall experience was positive, exceeding the expectations of many, especially those deriving clinical benefit. Results highlight variation in support/information needs, with desire for more robust communication, especially around personal trial completion/next steps.



