the CHURCHILL fellowship

FROM UNCERTAINTY TO UNDERSTANDING: ENHANCING HOLISTIC SUPPORT FOR CANCER OF UNKNOWN PRIMARY (CUP) PATIENTS

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ABOUT THE AUTHOR

Alison Taylor is a nurse consultant at The Clatterbridge Cancer Centre, Liverpool, UK, with over 25 years of experience in cancer care. She specialises in acute oncology and has led local, regional, and national initiatives to improve care for people with Cancer of Unknown Primary (CUP) and Malignancy of Unknown Origin (MUO). Alison is a board member of the UK Acute Oncology Society and chairs its MUO subgroup. She is also a member of the World Cancer of Unknown Primary Alliance (WCA), expert panel.

NHS The Clatterbridge Cancer Centre NHS Foundation Trust

UKAOS UK Acute Oncology Society

ABBREVIATIONS/GLOSSARY

AO	Acute Oncology
CBT	Cognitive Behaviour Therapy
CF	Churchill Fellowship
CUP	Cancer of Unknown Primary
ESMO	European Society of Medical Oncology
GTAB	Genomic Tumour Advisory Board
MDT	Multi-Disciplinary Team
MUO	Malignancy of Unknown Origin
NCRAS	National Cancer Registry and Analysis Service
NHS	National Health Service
NSS	Non-Specific Services
Peter Mac	Peter McCallum
PPIE	Patient and Public Involvement and Engagement
QR	Quick Response
UK	United Kingdom
VARN	Victoria Affiliated Research Nurses
WGS	Whole Genomic Sequencing
CMCA	Cheshire and Merseyside Cancer Alliance

EXECUTIVE SUMMARY

This Churchill Fellowship report presents findings and actionable recommendations to improve the care of people with Cancer of Unknown Primary (CUP), focusing on psychological and emotional support. Drawing on international research and site visits to Australia, and The Netherlands, the report identifies best practices in multidisciplinary care, genomic medicine, and patient engagement that can be adapted to the UK context.

RECOMMENDATIONS

- **Establish dedicated CUP Nurse roles within oncology teams** to provide consistent, personalised report.
- **Expand genomic profiling services** and establish Genomic Tumour Advisory Boards (GTABs) to support decision-making for complex cases.
- **Integrate early palliative care** into CUP care pathways to improve quality of life from diagnosis onward.
- **Develop and distribute tailored support resources**, including digital tools and self-care apps, to empower patients and caregivers.
- **Create a national consumer group or patient parliament** to engage CUP patients in healthcare decisions, research, and policy development.
- **Address Inequality in Care Pathways:** standardise care pathways to reduce regional disparities in CUP diagnosis and treatment, ensuring equitable access to services, particularly in rural and underserved areas.
- **Promote Excellence through Regional Centres of Excellence:** Establish regional Centres of Excellence for CUP care, modelled after the SUPER sites in Australia, to advance research, share best practices, and improve clinical outcomes across regions.
- **Implement standardised diagnostic pathways for CUP based on international guidelines**, ensuring timely and coordinated care.

The insights gained from this fellowship serve as a foundation for transforming CUP care in the UK, offering innovative solutions that not only address clinical needs but also prioritise psychological well-being. By adopting these recommendations, we can build a more supportive, equitable, and patient-centred care model for CUP patients, ensuring they receive the care, resources, and support they need to navigate their diagnosis with dignity and confidence.

INTRODUCTION

Cancer of Unknown Primary (CUP) is a rare and complex condition in which metastatic cancer is diagnosed but the original site of the cancer (the primary tumour) cannot be identified (Greco et *al*., 2012). The uncertainty surrounding a CUP diagnosis presents significant challenges for both patients and healthcare professionals, with patients often facing not only the physical burden of the disease but also the psychological and emotional toll of living with an unknown prognosis (Wagland et al., 2017). Despite advancements in medical research, there is still a lack of standardised care pathways and psychological support services specifically tailored for CUP patients (Wolyniec et *al.*, 2022).

The aim of this report is to share the findings and insights gathered from a Churchill Fellowship that focused on exploring innovative psychological and emotional support models for CUP patients. During the fellowship, research was conducted in Australia, and the Netherlands to find effective care strategies and support mechanisms. By investigating how different healthcare systems approach CUP care, this fellowship looks to highlight best practices and provide actionable recommendations for improving the care, support, and overall well-being of CUP patients globally, particularly in the UK.

BACKGROUND TO THE PROJECT

Cancer of Unknown Primary (CUP) is a challenging diagnosis for both patients and healthcare providers. It occurs when cancer cells are detected in the body, but the primary site of the cancer cannot be found through standard diagnostic procedures (Brewster et *al*., 2014). This uncertainty can have a profound psychological impact on patients, who often experience heightened anxiety and distress due to the lack of a clear prognosis and treatment plan (Wolyniec et *al*., 2023). CUP is considered a rare and complex cancer, and as such, there are limited established care pathways, particularly in the psychological and emotional support areas(Wolyniec et al., 2022). In many healthcare systems, CUP remains an under-recognised condition, which can lead to delays in diagnosis and the provision of adequate care (van der Strate et *al*., 2023).

The need for innovation in how CUP is managed, both in clinical and psychological support, led me to select two countries Australia, and the Netherlands for this research. These countries were chosen because they are leading approaches to CUP care, particularly in terms of integrating psychological support, genetic profiling, and multidisciplinary care. Each of these nations has made significant strides in CUP care, but in different ways that can provide valuable insights.

Australia, through initiatives such as the SUPER-NEXT study (Guccione et al., 2022), has been at the forefront of integrating genomic profiling into clinical decision-making. The research into real-time genomic sequencing has shown great promise in improving outcomes for CUP patients by finding potential therapeutic targets. In addition, Australia has shown a commitment to equity in healthcare delivery, with a focus on overcoming geographical barriers and providing equitable access to quality care, especially in remote and underserved areas. The SUPER-ED trial aims to improve care for patients with suspected metastatic cancer of unknown primary by streamlining diagnosis and treatment through a standardised care model. This approach seeks to reduce time to diagnosis, enhance patient experience, and increase access to appropriate therapies (Ugalde et *al*., 2025a). The Netherlands, known for its progressive healthcare system, has been a leader in cancer care and palliative services. Their focus on integrated care and patient-centred approaches, especially in terms of psychological support, provides valuable lessons for managing CUP. By assessing their frameworks, this fellowship aimed to explore how these models can be adapted to the UK context.

AIM

The aim of my fellowship is to explore and identify effective psychological and emotional support models for individuals diagnosed with Cancer of Unknown Primary (CUP). The goal is to improve the quality of care provided to these patients, as well as their families and carers, ensuring that their psychological and emotional needs are met comprehensively and equitably.

OBJECTIVES

- Investigate Current Support Programmes: Research existing psychological and emotional support models for CUP patients in Australia and the Netherlands, identifying best practices and innovative approaches.

- Explore Integration in Multidisciplinary Care: Assess how psychological support is incorporated into oncology teams and multidisciplinary care frameworks for CUP patients.

- Explore Digital Innovations: Investigate the role of telehealth and digital platforms in delivering psychological support to CUP patients, enhancing accessibility and equity of care.

- Engage with Experts and Build Collaborative Relationships: Establish and strengthen relationships with leading healthcare providers, researchers, and support organisations working in the field of oncology and CUP care.

CONTEXT OF THE UK

Cancer of Unknown Primary (CUP) accounts for around 3-5% of cancer cases in the UK, with approximately 6,000 new diagnoses annually (Cancer Research UK, 2023). Despite its prevalence, CUP care remains under-researched and lacks standardised pathways (CRUK, 2020). The uncertainty of the cancer's origin often leads to reactive treatment and delayed decisions, compounded by limited tailored support services for patients and their families.

The National Institute for Health and Care Excellence (NICE) provides guidelines (NG12, CG104) recommending rapid diagnostic work-up for Malignancy of Unknown Origin (MUO) and CUP, including imaging, pathology, and multidisciplinary team (MDT) involvement (NICE, 2023). However, access to dedicated MUO/CUP services and specialist rare cancer teams varies widely across the NHS, resulting in inconsistent care quality and inequitable access to psychological and supportive services.

While the NHS has advanced cancer care overall, CUP patients frequently face gaps in holistic and psychological support due to the absence of a national strategy and uniform care standards. Addressing these issues requires improved implementation of NICE guidelines, expansion of specialist CUP services, and development of comprehensive emotional support tailored to this patient group.

By investigating the approaches to CUP care in Australia, and the Netherlands, this research aims to identify best practices that could be adapted to the UK context. Learning from these countries will allow for the development of a more comprehensive care model that addresses both the clinical and psychological needs of CUP patients. This research will also inform policy recommendations and offer strategies for integrating multidisciplinary care and technological innovations into UK services, ultimately improving outcomes for CUP patients and their families.

EXPERIENCE AND LEADERSHIP IN CANCER OF UNKNOWN PRIMARY (CUP) SERVICES

Over the past 13 years, I have gained experience working in the field of Cancer of Unknown Primary (CUP). During this time, I have seen the profound psychological toll a CUP diagnosis can have on patients. I believe this psychological impact is more significant than in many other cancer diagnoses, largely due to the high levels of uncertainty and lack of definitive answers associated with CUP, this has been demonstrated in patient experience research whilst limited to small studies, capture that CUP patients experience high levels of anxiety, depression and uncertainty (Richardson et al., 2015; Wagland et al., 2017; Wolyniec et al., 2022; Wolyniec et al., 2023; Boyland and Davis, 2008; Ugalde et al., 2025b). Seeing the struggles and inequity of this group of patients has fuelled my dedication to improving the care and support available to people with CUP.

In my current role, I combine clinical expertise with strategic oversight, serving as the CUP Site Reference Group Lead at the Clatterbridge Cancer Centre. This

position has provided me with the opportunity to lead critical initiatives aimed at enhancing CUP services. I have successfully reviewed and improved the CUP multidisciplinary team (MDT) framework, optimised the regional care pathway, and redeveloped the local CUP service. These efforts have been instrumental in streamlining patient care, improving outcomes, and fostering collaboration among healthcare professionals. This has increased access to research and clinical trials such as CUP COMP (Conway et al., 2024) and EGG CUP both trials looking at genomic testing using ctDNA.

The CUP service at The Clatterbridge Cancer Centre also has the support of a part time clinical support worker role, who is essential to providing holistic care. I also support the CUP team clinically alongside two medical oncologist colleagues.

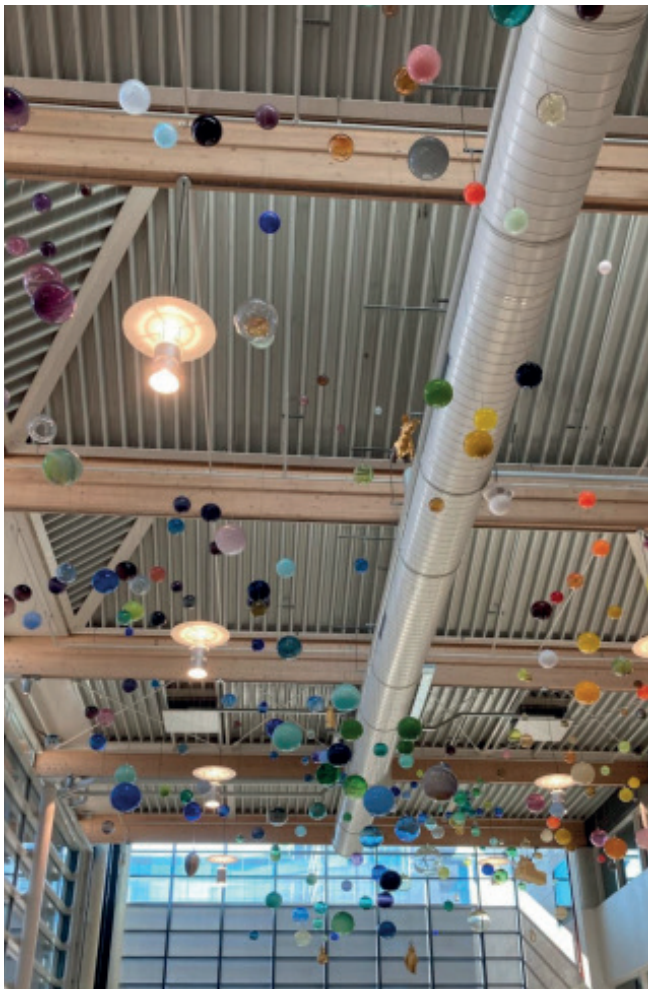
GLOBAL INSPIRATION AND COLLABORATION IN CUP CARE AND RESEARCH

My decision to travel to Australia was motivated by the internationally recognised leadership of the Peter MacCallum Cancer Centre (Peter Mac) in the management and research of Cancer of Unknown Primary (CUP). Supported by the Australian government, two landmark national studies SUPER and SUPER-NEXT, that have sought to transform CUP management by integrating comprehensive genomic profiling into routine clinical assessment and decision-making.

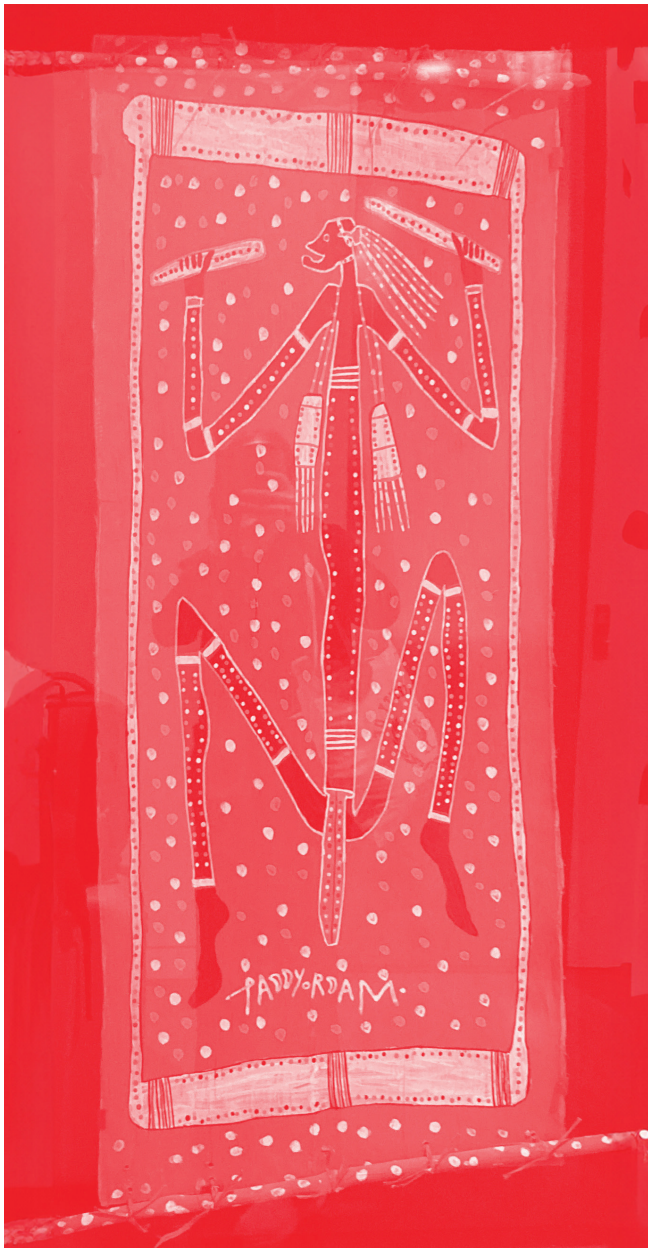
The SUPER-NEXT study specifically investigates the rapid implementation of clinically actionable genomics to improve patient outcomes, while also evaluating the societal and health economic implications of these technologies (Wolyniec et al., 2023). This national approach is grounded in a strong commitment to equity, ensuring that innovative CUP care is accessible across Australia's diverse and geographically dispersed population.

During my visit, I engaged with multiple clinical and research teams across Australia, gaining first-hand insight into the operationalisation of genomics within CUP care pathways. This included observing multidisciplinary clinical workflows, understanding the integration of genomic data into patient management, and exploring strategies to maintain equitable access despite significant geographical challenges. Notably, the Australian teams adopt a holistic approach that addresses not only the clinical and economic aspects of CUP management, but also the psychological impact of diagnosis, genomic testing, and the inherent uncertainty faced by patients.

By visiting multiple sites across Australia that contributed to this pioneering work, I gained invaluable insights into how CUP care is effectively managed over such a vast geographical area while supporting equity and innovation. This experience involved working closely with clinical and research teams, observing patient care firsthand, and understanding the integration of genomics into clinical workflows. Importantly, I learned about the psychological impact of CUP, genomic testing, and living with uncertainty, an area that the Australian teams are addressing comprehensively alongside their focus on societal and economic outcomes. The next step for the team is SUPER ED (Ugalde et al., 2025a).



INTERNATIONAL COLLABORATION AND FELLOWSHIP EXPERIENCE



PURPOSE OF THE REPORT

The purpose of this report is to document and share the outcomes of my fellowship experiences and the insights gained from this journey. By disseminating these findings, the report aims to contribute to the body of knowledge surrounding CUP care and propose actionable recommendations to address gaps in psychological support. It is intended to inform practice, influence policy, and inspire system improvements both in the UK and within the global CUP community. Much of the learning from the Fellowship is transferable to other areas of cancer care, however for the purpose of report I have focused on just the Cancer of Unknown Primary group.

APPROACH AND METHODS

My travels included 5 weeks in Australia – with site visit and shadowing clinical teams, visiting Melbourne, Peter MacCallum, The Olivia Newton John Cancer Centre, Victoria Associated Research Nurses (VARN) conference, Brisbane, Royal Brisbane Hospital, Sydney, North Shore hospital, WestMead, Darwin, Royal Darwin Hospital, and Geelong.

Netherlands visits included the Amsterdam Cancer centre Amsterdam, Antoni van Leeuwenhoek, Netherlands cancer Institute Amsterdam, Erasmus Rotterdam, World Cancer of Unknown Primary and Missie Tumour Onbekend founder, Waynta Minnaard.

To capture the data and insights underpinning this report the following methods of data collection included:

- **Narrative and Observational Approaches**
  Spending time with healthcare professionals, support staff, researchers, and patients to observe and understand clinical practices, support mechanisms, and patient care pathways.

- **Shadowing and Semi-Structured Interviews**
  Shadowing professionals in their work environments and conducting semi-structured interviews using a set series of questions to explore perspectives and experiences.

- **Field Notes and Observations**
  Maintaining detailed field notes to document observations and interactions, providing qualitative data for analysis.

- **Digital Documentation**
  Using the Journi blog app to chronicle my journey, capturing photos and reflections in real-time. This platform enabled me to document experiences systematically while sharing updates with friends, family, and colleagues. The blog can be accessed at the following link: Journi Blog.

This combination of approaches allowed for a comprehensive exploration of the psychological and emotional support needs of CUP patients and their caregivers, while also providing opportunities to observe and engage with innovative practices in real-world settings.

In addition to my time in Australia, my fellowship enabled collaboration with leading CUP research teams in the Netherlands, particularly at Erasmus MC Cancer Institute in Rotterdam. Erasmus MC is internationally recognised for its multidisciplinary approach and pioneering work in integrating advanced genomic technologies and innovative imaging into CUP management. Their research includes the use of next-generation sequencing and liquid biopsy to improve diagnostic accuracy and guide personalised treatment strategies.

A notable development at Erasmus MC is their leadership in the multi-centre, investigator-initiated FAPI PET trial, which aims to improve the detection of primary tumours in CUP patients using [18F]F-FAPI PET-CT imaging (Droogers, 2025). This trial, open since July 2024 and recruiting across six major Dutch cancer centres including Erasmus MC. It aims to evaluate the diagnostic yield of FAPI PET-CT compared to conventional imaging. The study hypothesises that FAPI PET-CT, which targets fibroblast activation protein highly expressed in many tumours, will significantly increase the rate of primary tumour identification in CUP, facilitating more targeted and effective therapies (Droogers, 2025)

The trial's design includes centralised image review and multidisciplinary discussion to ensure rigorous assessment and integration of findings into patient management. Early evidence suggests that FAPI PET-CT may outperform standard FDG PET-CT in sensitivity and accuracy, with the potential to impact treatment decisions and improve outcomes for CUP patients (Willemse et al., 2024).

Through my engagement with Erasmus MC, I gained valuable insights into the Dutch model of CUP care, which combines genomic and advanced imaging innovations with robust national guidelines and a strong emphasis on equitable access. This experience has informed my understanding of how cutting-edge diagnostics can be implemented within a holistic, patient-centred framework to address the unique challenges of CUP.

APPLYING GLOBAL INSIGHTS TO THE UK

In the UK, awareness and resources for CUP are limited, both for medical professionals and the public. There is a pressing need to enhance awareness, improve resources, and provide equitable and innovative care for CUP patients. Learning from the Australian, and Dutch approaches has provided me with valuable knowledge and ideas to address these gaps.

The integration of genomics, equitable care delivery, and comprehensive psychological support seen internationally serves as a model for improving CUP services in the UK. Sharing these learnings and advocating for similar advancements could significantly help patients and professionals alike, ultimately improving outcomes and quality of life for individuals affected by CUP.

KEY FINDINGS/THEMES

The findings from my fellowship are centred on improving the psychological and emotional support for patients with Cancer of Unknown Primary (CUP) and their caregivers. Key themes have emerged from my observations, discussions, and analysis of practices across Australia, and the Netherlands. Case study examples are used to illustrate the critical role of psychological support in the care of patients with Cancer of Unknown Primary (CUP). To protect the privacy and confidentiality of individuals, all case details and names have been anonymised.

1. NAMED COORDINATOR ROLE

Observation: Many services I visited emphasise the importance of a dedicated CUP nurse or named coordinator who serves as the primary point of contact for patients. In Australia, CUP coordinators streamline care, providing tailored guidance and emotional support while ensuring continuity throughout the diagnostic process. The SUPER ED trial is currently collecting evidence to demonstrate the importance of this role.

Analysis: This role fosters trust and reduces patient anxiety by offering a consistent source of information and support. However, in some instances, the role was combined with other responsibilities, potentially diluting its effectiveness.

Recommendation: The UK should establish a formalised, named CUP nurse role or clinical support worker role within oncology teams, ensuring it is not an add-on responsibility but a dedicated position with clear job descriptions.

CASE STUDY ONE

John, an 82-year-old man, presented with new liver metastases and was referred to the CUP team at Peter Mac. Despite extensive investigations, no primary tumour could be identified. The CUP team facilitated a thorough multidisciplinary team (MDT) discussion, enabling the development of a personalised treatment plan that included palliative care support. Psychological counselling was also offered to help John and his family navigate the emotional challenges of his diagnosis. He was given the name and contact number for the CUP nurse who supported him both emotional, psychological but also with practical things such as re-arranging appointments and organising medications.

Introducing the CUP Keyworker/Support Nurse

A pivotal addition to John's care was the involvement of a dedicated CUP keyworker/support nurse. From the point of referral, the keyworker became John's consistent point of contact, guiding him and his family through the complexities of the CUP pathway.

The Value of a CUP Keyworker/Support Nurse

1. Continuity and Coordination of Care

During my Churchill Fellowship, I observed that Australian CUP clinics routinely assign a keyworker or specialist nurse to each CUP patient. This role is central to ensuring seamless communication between the patient, family, and the wider MDT.

LEARNING APPLIED

- The keyworker coordinated John's appointments, investigations, and follow-up, reducing the risk of missed information and fragmented care.
- She acted as a liaison between different specialties, ensuring that recommendations from the MDT were clearly communicated and implemented.

2. Personalised Information and Advocacy

A CUP diagnosis is often confusing and overwhelming. Keyworkers in leading Australian clinics provide tailored information, answer questions, and advocate for patient preferences.

LEARNING APPLIED

- John and his family received clear, accessible explanations about his diagnosis, the purpose of further investigations, and the rationale for his treatment plan.
- The keyworker ensured that John's wishes and concerns were heard and addressed during MDT discussions.

3. Emotional and Practical Support

The uncertainty of CUP can be distressing. The keyworker provided ongoing emotional support, checked in on John's psychological wellbeing, and facilitated access to counselling and community resources.

LEARNING APPLIED

- The keyworker helped normalise John's feelings of anxiety and uncertainty, offering reassurance and practical coping strategies. She also supported John's family, recognising the impact of the diagnosis on carers and loved ones.
- She also providing signposting to other services for emotional and psychology support, such as the well-being centre and Men's Shed.

4. Navigating Complex Pathways and Services

CUP patients often require input from multiple specialties and services. The keyworker's role included helping John navigate these pathways, ensuring timely referrals and minimising delays.

LEARNING APPLIED

- The keyworker arranged for early palliative care involvement, as well as prompt access to psychological support, mirroring the integrated approach seen in Australian CUP services.
- She also provided information about local support groups and community resources, helping John and his family feel less isolated.

Reflecting Fellowship Learning

This case, enhanced by the involvement of a CUP keyworker/support nurse, exemplifies the best practices observed during my Churchill Fellowship:

- Dedicated keyworker roles are standard in high-performing Australian CUP clinics, providing essential continuity, advocacy, and support.
- Patients and families benefit from having a single, trusted point of contact who can guide them through the diagnostic and treatment journey.
- Integrating keyworkers into the CUP pathway improves patient experience, reduces distress, and ensures that care is truly personalised and coordinated.

Recommendations for UK CUP Services

- Establish dedicated CUP keyworker/support nurse roles as standard practice, ensuring every CUP patient has a consistent advocate and guide.
- Incorporate keyworkers into MDT meetings and care planning, recognising their unique insights into patient needs and preferences.
- Provide training and resources to support keyworkers in delivering high-quality, compassionate, and culturally competent care.

John's case demonstrates the transformative impact of a CUP keyworker/support nurse, as championed in Australian models and supported by Churchill Fellowship learning. Embedding this role in UK CUP pathways would ensure that all patients receive the coordinated, personalised, and compassionate care they deserve.

2. ACCESS TO TAILORED RESOURCES

Observation: Patients in Australia and the Netherlands benefit from tools such as self-care apps, cognitive behavioural therapy (CBT) booklets, diaries, and short courses focused on coping mechanisms. For example, a well-being centre in Melbourne provided access to digital resources and QR codes linking to symptom management tools. The Your Thoughts Matter booklet for patients to use to guide their clinical consultations also empowered patients to ask the questions that matter to them. This work also provided communication training to staff to help guide consultations using the booklet. This intervention has been proven to improve patient experience, reduce consultation time and improve patient satisfaction with the information they receive.

Analysis: Tailored resources empower patients to take an active role in their care while addressing psychological challenges. However, the availability of such resources in the UK that are tailored for CUP are limited.

Recommendation: Develop and distribute digital and printed resources for CUP patients, including patient information sheets, mood and sleep trackers, self-help guides, and apps.

3. SET DIAGNOSTIC PATHWAYS AND MULTIDISCIPLINARY DECISION-MAKING

Observation: In all countries visited, diagnostic pathways for CUP were clearly defined based on European Society for Medical Oncology (ESMO) guidelines. Multidisciplinary teams (MDTs) were integral to making complex decisions, incorporating oncologists, radiologists, pathologists, and other specialists.

Analysis: Structured pathways reduce diagnostic delays and improve patient outcomes, while MDT discussions ensure comprehensive case reviews. However, some UK services lack formalised pathways, leading to inconsistent care. Improving the diagnostic pathway and the length of time patients waited will reduce unnecessary tests, leading to earlier diagnosis, which reduces waiting times and anxiety for patients.

Recommendation: Implement standardised diagnostic pathways for MUO and CUP based on ESMO guidelines in the UK and ensure every CUP case undergoes MDT review to enhance decision-making.

CASE STUDY TWO

Jean, a 59-year-old woman, dissatisfied with her initial healthcare provider due to poor communication and care, sought a second opinion. The CUP team's comprehensive review identified missed diagnostic opportunities and treatment delays. By developing a clear care pathway and offering psychological support, the team restored her trust in the healthcare system.

1. Holistic, Patient-Centred Care

During my Churchill Fellowship, I observed that Australian CUP clinics routinely assign a keyworker or specialist nurse to each CUP patient. This role is central to ensuring seamless communication between the patient, family, and the wider MDT.

FELLOWSHIP INSIGHT

International best practices highlight the importance of treating CUP patients holistically, addressing both clinical and psychological needs.

APPLICATION

In this case, the team not only focused on accurate diagnosis and timely treatment but also prioritised psychological support. This mirrors models observed during the Fellowship, where multidisciplinary teams integrate mental health care, improving patient outcomes and satisfaction.

2. Timely and Accurate Diagnosis

FELLOWSHIP INSIGHT

Delays and missed opportunities are common in CUP cases due to diagnostic complexity. Leading centres use streamlined, protocol-driven diagnostic pathways.

APPLICATION

The CUP team's comprehensive review and pathway development directly reflect the structured approaches seen during the Fellowship. By implementing clear protocols, they reduced delays and improved diagnostic accuracy.

3. Effective Communication and Shared Decision-Making

FELLOWSHIP INSIGHT

Patient trust is built through transparent, empathetic communication and involving patients in care decisions.

APPLICATION

The team's patient-centred communication restored the patient's trust, demonstrating the value of shared decision-making and clear information —key themes from the Fellowship.

4. Multidisciplinary Team (MDT) Approach

FELLOWSHIP INSIGHT

MDT meetings with input from oncology, pathology, radiology, and palliative care are standard in high-performing CUP services.

APPLICATION

The case review involved a comprehensive, multidisciplinary assessment, ensuring all aspects of the patient's care were considered, as recommended in international CUP models.

5. Restoring Trust in Healthcare

FELLOWSHIP INSIGHT

Restoring trust after negative experiences is crucial for patient engagement and adherence to treatment.

APPLICATION

By addressing previous shortcomings and providing compassionate, coordinated care, the team rebuilt the patient's confidence in the system, a direct reflection of patient advocacy and support strategies observed abroad.

This case demonstrates how learning from the Churchill Fellowship, specifically, international best practices in CUP care can transform patient experiences. By introducing structured diagnostic pathways, holistic support, and patient-centred communication, we can significantly improve outcomes and restore trust for patients with complex cancer diagnoses.

4. INTEGRATION OF GENOMICS AND RESEARCH

Observation: The SUPER-NEXT study in Australia showcased how real-time genomic profiling is transforming CUP diagnostics and treatment. On the visits to both Australia and the Netherlands, the Genomic tumour advisory boards (GTABs) were pivotal in interpreting complex results and guiding decisions in a multiple disciplinary team approach.

Analysis: Genomics offers significant potential to personalise CUP care, but patient education and staff training are essential to maximize its impact.

Recommendation: Expand genomic profiling in the UK, accompanied by robust patient education materials and training programs for clinicians. Establish dedicated GTABs to support complex cases, which clear written outcomes from the GTAB to the treating clinical team.

5. HOLISTIC SUPPORT AND EARLY PALLIATIVE CARE

Observation: Services in the Netherlands and Australia prioritise early referrals to palliative or enhanced supportive care. Well-being centres were also essential to holistic care and provide access to a wide range of resources, including psychological counselling and support groups to support the holistic needs of patients. PATIO (Patient Information Centre Oncology) at Erasmus MC Cancer Institute in Rotterdam exemplifies a dedicated approach to meeting the informational and supportive care needs of oncology patients and their families throughout the cancer journey.

Analysis: Early integration of palliative and supportive care not only improves quality of life but also helps patients and families navigate the medical and emotional uncertainty of a CUP diagnosis. Access to information, psychological support, and peer groups delivered through dedicated centres empowers patients, reduces distress, and enhances overall care experience.

Recommendation: Integrate early referral to palliative or enhanced supportive care as a standard component of CUP pathways in the UK.

- Establish dedicated information and support centres, modelled on PATIO and Maggie's Centres, within cancer services to provide accessible, holistic support for CUP patients and their families.
- Ensure that all CUP patients are routinely offered early access to palliative care, psychological counselling, and peer support, regardless of prognosis.
- Embed these services within multidisciplinary CUP teams to facilitate seamless coordination and timely intervention.
- Promote awareness among clinicians and patients about the benefits of early supportive care, shifting the focus from end-of-life care to holistic well-being and empowerment from the point of diagnosis.

By adopting these international best practices, UK CUP pathways can deliver more compassionate, patient-centred care and improve outcomes for patients and their loved ones.

CASE STUDY THREE

Peter, a 67-year-old man at Westmead Hospital was referred to palliative care immediately after his Cancer of Unknown Primary (CUP) diagnosis, before seeing oncology. This premature referral caused confusion and distress for him and his family, who felt unsupported in understanding his treatment options. The CUP team intervened, arranged a prompt oncology review, and improved future referral processes to ensure better communication and timing.

1. Communication Protocols and Preventing Conflict

FELLOWSHIP INSIGHT

The observation with clinical teams found that clear, compassionate communication is essential to prevent distress and conflict in palliative care situations. International models emphasize structured protocols for discussing prognosis, treatment options, and the role of palliative care, ensuring patients and families are informed and supported at every step.

APPLICATION

The confusion and distress experienced by the patient and family in this case directly resulted from a lack of clear communication about the intent and timing of palliative care. By intervening with an expedited oncology review and improving communication protocols, the team reflected best practice models that prioritise patient and family understanding and shared decision-making.

2. Integrated, Collaborative Care Pathways

FELLOWSHIP INSIGHT

Global best practice in cancer care highlight the importance of integrated care pathways where oncology and palliative care teams collaborate closely. This ensures referrals are appropriately timed and that patients do not feel abandoned or given up on, but instead receive holistic, coordinated care. This is not just unique to CUP but for all patients with cancer.

APPLICATION

The palliative care team's role in coordinating oncology and palliative input and reviewing referral timing, mirror international models where multidisciplinary teams work together to support patients, rather than acting in silos. This approach reduces confusion, builds trust, and ensures care is both timely and appropriate to the patient's needs.

3. Patient and Family-Centred Approach

FELLOWSHIP INSIGHT

This example emphasizes that care should be designed around the needs and expectations of patients and families, incorporating their perspectives into planning and delivery. Early palliative care involvement should be explained as supportive and not as a sign that curative options are exhausted.

APPLICATION

By addressing the family's distress and clarifying the care pathway, the palliative care team demonstrated a patient-centred philosophy, ensuring that future referrals would be accompanied by clear explanations and support. This aligns with Fellowship learning that patient and family engagement is critical for high-quality care.

This case illustrates how Churchill Fellowship learning, particularly in communication, integrated care, and patient-centred approaches can transform the experience of CUP patients. By applying international best practice, the palliative team improved patient and family understanding, reduced distress, and enhanced the coordination of oncology and palliative care. These changes directly reflect the core principles and innovations observed through the Fellowship, demonstrating the value of global learning in local service improvement.

6. PATIENT ENGAGEMENT AND CONSUMER GROUPS

LEARNING FROM THE CHURCHILL FELLOWSHIP APPLIED

Observation: In Australia, consumer groups and patient parliaments played an active role in shaping research and influencing healthcare strategies.

Analysis: Involving patients in decision-making empowers them and ensures care models are patient-centred.

Recommendation: Establish a UK-based consumer group or patient parliament for CUP to provide feedback, share experiences, and guide service improvements.
Demonstrating Churchill Fellowship Learning: Consumer Advocacy and Co-Design in CUP Care.

CONSUMER GROUP EXAMPLE

Cindy Bryant, Lead of the CUP consumer group in Melbourne, recounted her late father's experience with CUP, highlighting significant gaps in care, specifically the absence of psychological support and poor communication about diagnostic uncertainty. Motivated by her father's journey, Cindy has championed consumer-focused initiatives such as patient feedback systems and educational resources, empowering patients to have a voice in shaping their care.

1. Embedding the Patient Voice in Service Design

FELLOWSHIP INSIGHT

International best practice, as observed during the Churchill Fellowship, underscores the importance of involving patients and families in the design and evaluation of cancer services. Consumer advisory groups, patient parliaments, and regular feedback mechanisms are integrated in leading CUP centres.

APPLICATION

Cindy's leadership in establishing consumer-focused initiatives directly mirrors these global models. By creating structured opportunities for patient feedback and engagement, the CUP community in Melbourne is ensuring that services are responsive to real-world patient needs and experiences.

2. Improving Communication Around Diagnostic Uncertainty

FELLOWSHIP INSIGHT

One of the most challenging aspects of CUP is managing diagnostic uncertainty. International centres of excellence invest in training clinicians to communicate uncertainty compassionately and clearly, reducing anxiety and fostering trust.

APPLICATION

Cindy's advocacy for better communication led to the development of educational resources for both patients and clinicians. This approach reflects Fellowship learning that honest, empathetic communication about uncertainty is crucial for patient wellbeing and engagement.

3. Prioritising Psychological Support

FELLOWSHIP INSIGHT

Leading CUP services incorporate routine psychological assessment and support from the point of diagnosis, recognising the unique distress CUP patients face. The can be done both formally using holistic needs assessments and informal by routine care conversations.

APPLICATION

The lack of psychological support and diagnostic pathways in Cindy's father's care highlighted a critical gap. Her subsequent advocacy has resulted in initiatives to embed psychological support into the care pathway, aligning with international best practices learned through the Fellowship.

4. Co-Production and Continuous Improvement

FELLOWSHIP INSIGHT

Observing first hand improvement in action from the patient parliament and the consumer group using co-production, where patients and clinicians work together to design, deliver, and improve services leads to more effective, sustainable changes in care.

APPLICATION

The creation of patient feedback mechanisms and educational resources, driven by consumer leadership, exemplifies co-production. This ensures that improvements are meaningful and directly address patient-identified priorities.

This case study powerfully demonstrates how Churchill Fellowship learning, particularly around consumer engagement, communication, and psychological support can drive meaningful change in CUP care. By embedding the patient voice and co-designing services, the CUP community is building a more compassionate, transparent, and responsive system, directly reflecting the innovations and best practices observed internationally.

7. ADDRESS INEQUALITY IN CARE PATHWAYS

PATHWAYS AND DOCUMENTS

Observation: Variations in care pathways and access to services across the UK result in inequalities in CUP diagnosis and treatment. Despite advancements in Australia and the Netherlands there were still inequalities in the care for patients with CUP across both countries and this was similar to the UK.

Analysis: Standardising care pathways ensures consistency and equity in the delivery of diagnostics, treatment, and support services, regardless of geographic location. Special attention is needed to address resource gaps in rural and underserved regions.

Recommendation: Develop and implement standardised CUP care pathways across the UK to reduce regional disparities. Ensure equitable distribution of resources and services, with targeted support for areas with limited access to healthcare.

CASE STUDY FOUR

A 52-year-old woman with Cancer of Unknown Primary (CUP), who spoke limited English, faced significant challenges navigating her diagnosis and treatment due to language barriers. The CUP team addressed these barriers by using interpreters, providing culturally sensitive resources, and arranging peer support from a bilingual community volunteer. This approach greatly improved her understanding and emotional well-being throughout her care journey.

LEARNING FROM THE CHURCHILL FELLOWSHIP APPLIED

1. Addressing Communication and Cultural Barriers

FELLOWSHIP INSIGHT

It is recognised that language and cultural barriers are persistent challenges in healthcare globally, often leading to misunderstandings, errors, and poorer outcomes for patients with limited English proficiency. Best practice internationally includes the systematic use of professional interpreters and culturally tailored resources to ensure patients can fully participate in decisions about their care.

APPLICATION

In this case, the CUP team's use of interpreters and culturally sensitive materials directly reflects these international best practices. This enabled the patient to understand her diagnosis and treatment options, supporting her autonomy and participation in care, key recommendations from Fellowship research.

2. Culturally Competent, Inclusive Care

FELLOWSHIP INSIGHT

Fellowship projects highlight that cultural competence goes beyond basic awareness training; it requires active policies and practices that promote equity, diversity, and inclusion at every stage of the care pathway. This includes recognising the unique needs of patients from diverse backgrounds and adapting services accordingly.

APPLICATION

By arranging peer support from a bilingual volunteer, the CUP team fostered a culturally safe environment and addressed the patient's emotional and social needs. This aligns with Fellowship learning that peer and community support can be transformative for non-English-speaking patients, improving both understanding and well-being.

3. Embedding Equity and Diversity in Practice

FELLOWSHIP INSIGHT

The Churchill Fellowship emphasises that equity, diversity, and inclusion must be embedded in all aspects of healthcare delivery, with a focus on removing barriers for marginalised groups. Sustainable change requires not only training but also system-level commitment to inclusive practice.

APPLICATION

The CUP team's approach proactively identifying and addressing language and cultural barriers, demonstrates a commitment to equity and inclusion, as advocated by the Fellowship. This ensures that all patients, regardless of language or background, receive high-quality, accessible care.

This case exemplifies how Churchill Fellowship learning, particularly around communication, cultural competence, and equity, can be applied to improve outcomes for non-English-speaking CUP patients. By integrating interpreters, culturally sensitive resources, and peer support, the CUP team provided truly patient-centred care, directly reflecting international best practice and the Fellowship's core values of diversity and inclusion.

8. PROMOTE EXCELLENCE THROUGH REGIONAL CENTRES OF EXCELLENCE

In all the countries visited and in the UK specialist centres are leading the way in improving care of people with CUP. Small hospitals/rural areas lack dedicated CUP teams, staff or MDTS, given the lack of resources and the complexity of CUP smaller hospitals need the links with the specialist centres.

This is especially for access to trials. The SUPER trial is a prime example of this, by having smaller hospitals open the trial across Australia, led by Peter Mac, this has improved awareness and resources in smaller hospitals , allowing focus on CUP that would not have been there without the trial, especially access to specialist tests such as genomic testing, ct DNA and FAPI PET CT scans.

Observation: The SUPER sites in Australia demonstrate the effectiveness of regional Centres of Excellence in advancing CUP care through research, clinical innovation, and best practice dissemination.

Analysis: Establishing Centres of Excellence enhances collaboration among multidisciplinary teams, promotes research, and provides a central hub for training and development. These centres ensure that innovations in CUP care are accessible nationwide.

Recommendation: Establish regional Centres of Excellence for CUP in the UK, modelled after Australia's SUPER sites. These centres would focus on research, training, and sharing best practices, ensuring the latest advancements in CUP management are implemented across the country.

IDEAS FOR FUTURE DEVELOPMENT

- **National CUP Support Network** Establish a national group comprising named CUP teams (oncologists, nurses, and support staff) to provide advice, second opinions, and resources.
- **Buddy System** Create a peer-to-peer support program connecting patients and caregivers through a "buddy" or pen-pal system.
- **Story Writing and Diaries** Offer professional story-writing services to help patients document their journey, providing emotional relief and fostering community.
- **Centralised Resources** Develop a national or international CUP website featuring patient stories, educational videos, and resources for both patients and professionals.
- **Digital platform** Development of a digital website or online platform to share CUP resources or the development of a CUP app for patients, carers and professionals.
- **CUP patient toolkit** Suite of resources for both healthcare professionals and also for people with CUP and those who care for them

OTHER INTERESTING FINDINGS AND AREAS FOR FURTHER WORK

FAPI PET Studies: Advancing CUP Diagnostics

Emerging evidence suggests that novel imaging modalities, such as 68Ga-FAPI and [18F] F-FAPI PET/CT, significantly improve the detection rate of primary tumours in patients with Cancer of Unknown Primary (CUP), especially when conventional imaging (CT, MRI, 18F-FDG PET/CT) is inconclusive (Willemse et al., 2024). Recent multi-centre studies have demonstrated that FAPI PET/CT can identify the primary tumour in a notably higher proportion of CUP cases compared to standard techniques, directly influencing treatment decisions and patient management (Droogers, 2025). Ongoing trials are further evaluating its clinical utility, with the potential to make minimally invasive cancer diagnostics more accurate and accessible for CUP patients.

Access to Circulating Tumour DNA (ctDNA) via Clinical Trials

The use of ctDNA analysis is expanding through clinical trial access, offering a promising avenue for molecular profiling in CUP. This technology enables the detection of actionable genetic alterations from a blood sample, which may guide targeted therapies even when tissue biopsies are limited or inconclusive. Broader trial participation and integration of ctDNA into routine diagnostics could enhance personalised treatment options and improve outcomes for CUP patients.

The Role of Artwork and the Importance of Surroundings

Patient and carer feedback highlights the positive impact of healing environments, including the integration of artwork and thoughtful design in clinical spaces. Such enhancements can reduce anxiety, foster a sense of

safety, and contribute to holistic well-being during the diagnostic and treatment journey (Lankston et al., 2010). Further work could explore how environmental factors and creative interventions support psychological resilience and patient experience, particularly for those facing diagnostic uncertainty.

Charities and Non-Hospital Support: WCA, PATIO

Charitable organisations and patient advocacy groups, such as the World CUP Alliance (WCA) and PATIO, play a critical role in bridging gaps in care. They provide information, peer support, practical assistance, and advocacy for CUP patients and families. These non-hospital resources are often essential for navigating complex care pathways, accessing second opinions, and ensuring that patient voices are heard in service development and policy.

Geographic Inequities: Lack of Local Services and Remote Access

CUP patients frequently report the need to travel long distances to access specialist services or obtain second opinions, which can delay diagnosis and treatment, increase financial burden, and exacerbate distress. There is a pressing need to expand local CUP services, develop telehealth pathways, and ensure equitable access to specialist expertise regardless of geographic location.

Language Barriers and Non-English-Speaking Patients

Patients for whom English is not a first language face additional challenges in understanding their diagnosis, treatment options, and navigating the healthcare system. Language barriers can result in poorer communication, reduced engagement, and suboptimal care. Expanding interpreter services, culturally tailored resources, and community-based peer support are necessary to ensure equitable care for all CUP patients.

Aboriginal CUP Patients: Cultural and Linguistic Challenges

Engaging Aboriginal patients with CUP presents unique challenges, particularly where there are no direct translations for concepts such as genomic testing. This can hinder effective communication about diagnostics and treatment and may contribute to lower participation in advanced testing or clinical trials. Culturally sensitive engagement strategies, co-designed educational materials, and partnerships with Aboriginal health workers are vital for reaching and supporting these communities.

SUMMARY OF RECOMMENDATIONS FOR FURTHER WORK:

- **Expand access to advanced imaging and molecular diagnostics** (FAPI PET/CT, ctDNA) through research and service development.
- **Investigate the impact of healing environments** and creative interventions on patient well-being.
- **Strengthen partnerships with charities and advocacy groups** to enhance non-clinical support.
- **Address geographic inequities** by developing local specialist services and telehealth pathways.
- **Improve language access and culturally competent care** for non-English-speaking and Aboriginal patients.
- **Develop and evaluate co-designed resources to support engagement** with hard-to-reach groups, ensuring that all patients benefit from advances in CUP care.

CONCLUSION

This fellowship has offered invaluable insights into effective psychological and emotional support models for patients with Cancer of Unknown Primary (CUP) and their caregivers. By studying best practices in Australia, and the Netherlands, I have identified key strategies to improve the quality of care for CUP patients in the UK and beyond.

Central to these findings is the importance of setting up a dedicated CUP nurse or named coordinator role to provide consistent, personalised support for patients. Equally critical is the development and implementation of standardised diagnostic pathways, based on ESMO guidelines, alongside robust multidisciplinary team (MDT) decision-making frameworks. These structures ensure prompt, evidence-based care and help the integration of genomics, a transformative tool in CUP diagnostics and treatment.

Holistic care emerged as another essential element, emphasising early referral to palliative or enhanced supportive care and the use of well-being centres that offer comprehensive resources. Digital innovations, such as telehealth platforms and self-help apps, further enhance accessibility and equity of care for patients, particularly in geographically diverse regions.

The fellowship also highlighted the value of patient engagement and empowerment. Consumer groups and patient parliaments, as seen in Australia, ensure that care models are patient-centred and responsive to the needs of individuals living with CUP. By involving patients and caregivers in decision-making and research, these initiatives strengthen trust and improve outcomes.

To bridge the gaps in UK CUP services, the following key recommendations have appeared:

SUMMARY OF RECOMMENDATIONS

→ **1. Establish Dedicated CUP Nurse Roles**
Integrate specialist CUP nurses within oncology teams to provide consistent, personalised, and holistic support for patients and their families.

→ **2. Standardise Diagnostic Pathways**
Implement clear, standardised diagnostic protocols for CUP, based on international best practice, to ensure timely, coordinated, and equitable care.

→ **3. Integration of genomics into standard pathways**
- Increase access to genomic profiling for CUP patients.
- Set up Genomic Tumour Advisory Boards (GTABs) to guide complex diagnostic and treatment decisions.

→ **4. Integrate Early Palliative Care**
Embed palliative care early in the CUP care pathway to enhance quality of life, symptom management, and psychological support from the point of diagnosis.

→ **5. Develop Tailored Support Resources**
Create and distribute bespoke support materials, including digital tools and self-care apps, to empower patients and caregivers with information and coping strategies.

6. Establish a National Consumer Group

Form a national patient parliament or consumer group to ensure CUP patients and carers are actively involved in healthcare decisions, research, and policy development. Promote patient involvement through consumer groups and peer-to-peer support systems.

7. Address Inequalities in Care

Standardise care pathways to reduce regional disparities and guarantee equitable access to CUP services, especially for rural and underserved populations.

8. Promote Regional Centres of Excellence

Develop regional Centres of Excellence for CUP (modelled on Australian "SUPER sites") to drive research, share best practices, and improve clinical outcomes across the UK.

By adopting these recommendations, the UK can build on international best practices to enhance the quality of care for CUP patients, ensuring it is equitable, innovative, and patient-focused. The knowledge and experiences gained through this fellowship underscore the critical need for multidisciplinary collaboration, research-driven strategies, and holistic approaches to support the unique challenges faced by CUP patients and their families.

The insights from this fellowship provide a foundation for transformative improvements in CUP care, inspiring a future where every CUP patient has access to the care, support, and resources they need to navigate their journey with confidence and dignity.

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