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The experiences of treatment and care for Polish gynaecological cancer patients at University Hospital Southampton

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Background

Over the past five years, the Gynaecological Cancer Care Team at University Hospital Southampton (UHS) has provided medical treatment and ongoing support to a growing number of patients from the Polish community. During this time, the team recognised that the experiences of these patients, and those of their families and care-givers, may differ significantly from those of White British patients. These differences could be shaped by a range of factors, including language barriers, cultural expectations, attitudes towards healthcare, and varying levels of familiarity with the UK health system.

With a genuine interest in delivering equitable and culturally sensitive care, UHS sought to deepen its understanding of the particular needs, challenges, and perspectives of Polish patients. In pursuit of this goal, they partnered with SOS Polonia, a local organisation that works closely with the Polish community. SOS Polonia was commissioned to conduct interviews with Polish women who had received treatment for gynaecological cancers, as well as with their family members and care-givers.

The aim of these interviews was threefold. They were to:

- Capture and document the lived experiences of these individuals
- Identify any areas where existing services could be improved
- Highlight gaps in local support networks that might be addressed in the future

This report by SOS Polonia presents the findings from six in-depth interviews and offers a series of recommendations to help shape more inclusive, responsive, and culturally aware cancer care for the Polish community in Southampton.

How we did it

Once the project was agreed upon, we worked collaboratively with colleagues from UHS and the Wessex Cancer Alliance (WCA) to review and refine the interview questions. Input from a member of our team who had personal experience with gynaecological cancer was particularly valuable in ensuring that the questions covered all the key aspects of treatment and support from a patient’s perspective.

Together with UHS and WCA, we co-produced an invitation letter in Polish, which was sent to ten patients. The letter invited them and their care-givers to take part in an interview and included a £25 voucher as a thank-you for their time. Following this initial outreach, three patients and care-givers expressed interest and agreed to be interviewed.To increase participation, we sent a second translated letter. This version provided more detail on the purpose and importance of the project and included anonymised quotes from the initial interviews to help illustrate the value of sharing these experiences. As a result, three additional participants came forward. A final outreach attempt was made via a brief text message, but no further interviewees were recruited through this method.

Throughout the recruitment period, the Lead Gynae Oncology Nurse from UHS also took the opportunity to speak directly with patients during clinic visits, offering further explanation about the project and encouraging participation.

All interviews were conducted in Polish over the telephone, using the prepared questions as a flexible guide. Each conversation lasted approximately 60 to 90 minutes.

Findings

From the patients' perspective

What works well before and during treatment and care

Starting from the point of diagnosis some patients stated that they experienced shock, which affected their ability to absorb information from the doctor.

- Patients interviewed spoke about how important it was to have the right kind of support, both emotional and practical, during their treatment journey. They highlighted the presence of the Macmillan specialist nurse during key stages of their care, especially around the time of diagnosis. Although receiving a cancer diagnosis was described by all as a deeply shocking and distressing moment, having a Macmillan specialist nurse present and in some cases, also being accompanied by a family member, was extremely helpful. This support allowed patients to begin to process the information more calmly once the initial shock had worn off. These supportive figures were able to help explain or clarify what was said, provide reassurance, and ensure that the patient didn't feel alone in facing such life-changing news.

- For some patients, language was a significant barrier, particularly during more complex or emotionally charged conversations. In these cases, having access to a professional interpreter was described as absolutely essential. Patients who had difficulty understanding or speaking English said they would have struggled to fully grasp the details of their diagnosis, treatment plan, or follow-up care without translation support. The interpreter service allowed them to communicate clearly, ask questions, and feel more in control of their care.

- Additionally, participants spoke warmly about the positive impact of interacting with Polish-speaking staff members. Even brief conversations in their native language helped patients feel more comfortable and reassured. It gave them a sense of familiarity and connection, which made the hospital environment feel less intimidating and more welcoming.

- All patients consistently reported that throughout every stage of their cancer treatment, they were clearly informed about who to contact if they had any problems, concerns, or questions. Whether it was a nurse, a doctor, or a support worker, they knew who their point of contact was and felt confident in reaching out whenever needed.

- Trust in the medical team came across strongly in all the interviews. Every patient expressed high levels of confidence in their doctors, describing them as professional, compassionate, and thorough. They felt that the doctors took time to explain the treatment options clearly, and they were reassured by the level of expertise and care shown. Importantly, patients felt that the treatment plans proposed to them made sense and were well-suited to their specific situation. This sense of being involved in their care decisions helped them feel safer and more secure during what was, for many, a frightening time.

- Patients also shared that they were given clear information about what symptoms to look out for during and after treatment, and they knew exactly who to contact if they experienced any of these symptoms. This information helped them feel more in control and better prepared for the recovery process and long-term self-monitoring.

- Practical support was another area where patients felt well cared for. Several patients mentioned that they received help managing physical side effects, such as hair loss, and were offered supportive resources following radiotherapy. Many expressed appreciation for having a space to talk openly and ask questions, including about their fears or beliefs around what may have caused the cancer. This openness created a sense of trust and emotional relief, allowing patients to feel seen and heard beyond just the clinical aspects of their care.

- The role of family and close friends was described as incredibly important by the women. Emotional support was just one aspect. Many relied on their loved ones for help with everyday tasks such as preparing meals, transportation to appointments, managing household chores, shopping, and simply being there with interest and care. This network of support made a significant difference to their ability to cope with the demands of treatment.

- In fact, patients shared that going through the experience of cancer had brought them closer to their families and friends. The illness, while undoubtedly difficult, acted as a catalyst for strengthening relationships, deepening bonds, and creating a renewed sense of connection and mutual support within their personal circles.

What could be done better

- When patients first received their diagnosis, many described experiencing an overwhelming wave of intense emotions. Their immediate reactions were often marked by a combination of shock, fear, devastation, helplessness, deep sadness, and heightened stress. These emotional responses were not only powerful at the time of diagnosis but continued to surface at various points throughout the treatment journey. While some individuals were very aware of these feelings as they occurred, others only recognised them in retrospect. In some cases, patients noted that they had unconsciously suppressed or ignored the emotional impact in order to focus on survival and physical recovery.

- Some patients felt there could have been more emotional guidance and support offered early in the process. They hoped that hospital staff, including doctors, nurses, and support workers, would be more proactive in acknowledging the emotional side of a cancer diagnosis and treatment. Some believed it would have been helpful for staff to explain that these feelings were a natural and valid part of the experience and to encourage them to seek emotional or psychological support without feeling ashamed or as though they were burdening others.

- For some patients, the experience of reaching out to the care team, particularly during or after the main phase of treatment, was marked by delays in communication or a lack of timely responses. This left them feeling discouraged and hesitant to seek further help. These individuals expressed that when their attempts to connect with the team went unanswered or took too long, it gave the impression that their concerns were not important, which in turn made them reluctant to voice future worries or needs.

- Some participants expressed a strong desire for more consistent and proactive contact from the hospital or support team throughout their treatment journey. This was especially true for patients who had limited support from family or friends. Due to the severity of their physical and emotional symptoms, they felt that being contacted regularly, even just to check in, would have made a significant difference in helping them feel cared for and not forgotten. These check-ins could have helped identify issues early and provided reassurance during what many described as an extremely vulnerable time.

- Language barriers also played a significant role in the challenges some patients faced, particularly when it came to accessing financial support. Those who had limited English proficiency found it especially difficult to complete the necessary paperwork and forms related to financial aid. Without assistance, this became a source of additional stress and anxiety during a period when their focus needed to be on healing.

- Spirituality and religion also emerged as important elements for some of the women interviewed. While not everyone mentioned this, several patients noted that having access to spiritual or religious support, such as a chaplain, prayer space, or someone to talk to about their beliefs, would have been meaningful and comforting. They felt that this aspect of support is often overlooked, yet it can play a vital role in helping people cope with the existential and emotional weight of a cancer diagnosis.

- Another important issue that came up in the conversations was the lack of understanding and communication around the use of vaginal dilators. These are medical devices used for some patients after certain types of cancer treatments to support vaginal health and maintain sexual function. One patient felt she was not adequately informed about why these were recommended or how to use them. As a result, this was confusing for her.

- Finally, a few women shared that speaking about cancer itself was deeply challenging. In particular, the stigma around the belief that "cancer is a death sentence," along with the fear and emotional pain tied to the illness, made open discussion difficult. They also struggled with the idea of becoming a burden to family and friends, as well as with shifting from a role of supporting others to one of receiving help. These internal conflicts and societal beliefs often created emotional barriers, sometimes leading to further isolation and making their journey feel lonelier than it needed to be.

From the care-givers perspective

What works well before and during treatment and care

- Carer-givers, whether they were family members or close friends, reflected on the experience of supporting their loved ones through diagnosis and treatment. They described the early stages, particularly the diagnostic phase, as being filled with uncertainty and emotional strain. However, many of them found great reassurance in the way the hospital team handled this critical time. They shared that one of the most comforting aspects was the clear and confident communication provided by the medical professionals. Knowing that their loved ones were receiving care from highly trained and experienced doctors, as well as being supported by a compassionate and professional hospital team, brought a sense of stability and trust.

- The timely development of a structured treatment plan also contributed to their peace of mind. It gave them something concrete to focus on and reduced feelings of helplessness. The carer-givers noted that the hospital staff showed empathy and kindness throughout, which made them feel included and acknowledged, not just as bystanders but as essential members of the support network. This helped them feel that their loved ones were in safe hands and that they, too, were being supported in their role as care-givers.

- Each care-giver expressed that they had been provided with clear and reliable information about who to contact in the event of any concerns or complications regarding the patient’s health. This clarity of communication helped them feel more prepared and confident in responding to any unexpected developments. They knew who to reach out to for advice or help, which helped alleviate some of the stress and anxiety associated with the caregiving role.

- The experience of supporting a loved one through cancer treatment had a profound impact on the personal relationships between patients and their care-givers. All of the care-givers shared that this journey brought them closer to the person they were supporting. They spent more time together, often having deeper conversations and sharing their fears, hopes, and emotional struggles. In some cases, this fostered a new level of closeness and mutual understanding that had not been there before the illness.

- This emotional deepening of the relationship was described as one of the few positive outcomes of an otherwise difficult time. Care-givers found themselves more in tune with the feelings and needs of their loved ones and, in turn, felt appreciated and needed. Some reflected that the cancer experience reshaped how they communicated and cared for one another, creating stronger, more empathetic bonds.

- Some care-givers also expressed a strong sense of fulfilment and purpose in being able to help. They felt grateful that they could provide tangible support in various ways, whether it was preparing meals, assisting with daily household tasks, offering transportation to and from medical appointments, or simply being present throughout the process. Being actively involved in the treatment journey gave them a sense of emotional connection. Rather than feeling powerless in the face of illness, they felt they were contributing in meaningful ways to their loved one's wellbeing and recovery.

What could be done better

- Some carers were not aware that emotional and practical support was available not only for the patients but also for themselves, at every stage of the treatment process. This knowledge would have given them confidence and a sense of security, as they knew they would not have to manage the challenges of caregiving alone. The accessibility of this support would have been especially important during more difficult moments, when patients faced side effects or emotional lows.

- Some care-givers shared that hearing the cancer diagnosis of their loved one was an emotionally overwhelming experience. They recalled feeling an immediate wave of shock, sadness, and anxiety upon receiving the news. These emotions often came suddenly and with great intensity, leaving them feeling unprepared and emotionally shaken. For those who also had to act as interpreters during medical appointments, translating complex and emotionally charged information between their loved one and the medical team, the emotional burden was even heavier. Balancing their own reactions while trying to communicate clearly and accurately added an additional layer of stress. They described this dual role as exhausting, both mentally and emotionally, as it left little room for them to process their own feelings in the moment.

- Some care-givers admitted that, in addition to feeling emotionally overwhelmed, they also felt uncertain and at times lost. They struggled with not knowing exactly what kind of emotional support their loved one would need from them or how to provide comfort in such a difficult situation. The lack of clear guidance on how to navigate their role as emotional anchors made some feel helpless, particularly when their loved ones were going through visible distress, fear, or physical suffering. This uncertainty sometimes led to feelings of guilt or self-doubt, as they questioned whether they were doing enough or doing the right things to help.

- Throughout the treatment period, care-givers reported experiencing a wide range of difficult emotions that stayed with them over time. While the initial shock may have softened, the sadness, worry, and emotional strain did not go away. Instead, these feelings evolved, appearing in different forms at different stages of the treatment journey. From dealing with the side effects of treatment, to supporting their loved ones during moments of pain or exhaustion, to accompanying them to hospital visits or managing daily responsibilities, care-givers were constantly engaged, both practically and emotionally.

- Despite their best efforts to remain strong and supportive, many admitted to feeling emotionally drained, particularly when there was little time or opportunity to care for their own mental health. The emotional demands of caregiving were often invisible but deeply felt. Still, they continued to stand by their loved ones, even when struggling silently with fear, fatigue, and emotional exhaustion.

Recommendations

- **Continue providing consistent and compassionate support to patients and their care-givers**

  It is important to maintain the current level of dedicated care and support that has been offered to both patients and their care-givers throughout the diagnostic and treatment journey. Patients and families have clearly valued the professionalism, empathy, and continuity provided by the clinical and support teams, and sustaining this standard of care will continue to offer reassurance and stability during what is often an emotionally and physically challenging time.

- **Ensure the ongoing availability of interpreters and language support for appointments**

  Access to interpreters has been highlighted as an essential part of the care experience, especially for patients and families who are not fluent in English. Continued provision of trained interpreters during appointments ensures that patients fully understand their diagnosis, treatment options, and follow-up care. Even if some patients or carers believe their English is strong during their initial appointments, it is recommended that support be offered at all stages of the process. This also helps clearer communication, enabling patients and care-givers to ask questions, express concerns, and engage more confidently in medical decisions.

- **Develop a practical, culturally sensitive guide for care-givers**

  To help care-givers better understand how to support their loved ones, it would be valuable to produce a guide specifically aimed at them. This guide could outline the types of emotional and practical support cancer patients may require throughout their treatment, what to expect during various stages of care, and how to care for their own wellbeing while fulfilling a supportive role. Ideally, it should include culturally relevant advice, be available in multiple languages, and offer simple, practical suggestions.

  It is recommended that the guide includes content on spirituality and religion. Additionally, a leaflet about the chaplaincy service could be included in the patient information pack to ensure patients are aware of the available support.

- **Introduce anonymous feedback tools, such as questionnaires or online forms**

  To ensure that patients and care-givers have the opportunity to share their experiences openly and honestly, it is recommended that anonymous feedback methods be incorporated actively into the care process. Regularly offering short, easy-to-complete questionnaires could encourage both groups to reflect on their care, highlight any unmet needs, and suggest improvements. Anonymity would help reduce fear of judgment or consequence, which may be a barrier for some to speak openly.

- **Provide regular reminders and clear information about available emotional and practical support**

  At each stage of the treatment journey - diagnosis, active treatment, follow-up, and recovery - it is essential to keep patients and their care-givers informed about what support is available to them. This includes emotional, psychological, financial, and practical resources. Patients should be gently reminded that seeking emotional help is not a sign of weakness but an important part of healing. Education around the value of emotional wellbeing should be integrated into ongoing care conversations.

- **Explore the level of informal support a patient has from family or friends**

  During assessments or initial appointments, consider asking patients whether they have a strong support network at home. For those who lack close family or friends nearby, it is important to ensure that they are offered alternative sources of support through NHS or local services. This helps prevent patients from becoming isolated and ensures they have someone to turn to for both emotional and practical help throughout their treatment.

- **Share this report with interview participants and invite ongoing dialogue**

  As part of a respectful and collaborative approach, the findings of this report should be shared with the patients and care-givers who contributed their experiences through interviews. They should be given the opportunity to provide additional thoughts, reflections, or clarifications. In addition, a message could be sent to individuals who were invited to participate but did not take part, offering them the chance to view the report and provide their own feedback. This inclusive approach ensures that the work remains grounded in real experiences and continues to evolve based on community input.

Conclusion

This report values many aspects and highlights a couple key recommendations to enhance the quality of care provided to patients and their caregivers:

- Feedback from patients and caregivers clearly indicates a strong appreciation for the current standard of empathetic, professional, and consistent support provided throughout the entire care journey.

- The continued availability of trained interpreters during medical appointments remains crucial for ensuring clear communication, particularly for patients and families who are not fluent in English, regardless of whether family members can assist with translation.

- The development of a practical, culturally sensitive, and multilingual guide for caregivers would be highly beneficial. Such a resource could support caregivers in their role while also promoting their own wellbeing.

- In addition, patients and caregivers should be regularly reminded of the emotional, practical, religious and financial support available to them routinely throughout the pathway.

- It is also recommended that healthcare teams routinely inquire about each patient’s informal support network and offer appropriate services to those who may be at risk of isolation.

UHS acknowledgements

SOS Polonia

We would like to express our heartfelt thanks to SOS Polonia for their outstanding contribution to this project. Their cultural insight, commitment, and direct engagement with patients and carers were vital to the success of the research. SOS Polonia's thoughtful and responsive approach helped build trust within the community and ensured the interviews were conducted with sensitivity and care.

Wessex Cancer Alliance

We also extend our sincere gratitude to the Wessex Cancer Alliance for their valuable input throughout the project. Their experience in patient engagement and co-production was instrumental in shaping the methodology and supporting inclusive collaboration. Their continued advocacy for patient-centred care made a significant impact.

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Appendix 1: Project brief

- **Download:** Project brief

Appendix 2: Interview guides for patients and care givers (English versions)

- **Download:** Interview guide for patients
- **Download:** Interview guide for care givers

Appendix 3: Reflections on the project from the project team

The project team was made up of three people from SOS Polonia, the UHS Macmillan Gynae Oncology Nurse Specialist and a Wessex Cancer Alliance on Patient Involvement Lead. After the interviews the team reflected on the project and lessons learnt. They are as follows:

What worked well

- SOS Polonia provided very thoughtful advice, guidance and input into the project, and were very responsive to challenges as they arose.

- As a first-time participant in a project of this nature, SOS Polonia entered the process without prior experience or established practices in this area. The organisation greatly benefited from the exceptional support and guidance provided by its two experienced project partners: the UHS Macmillan Gynaecology Oncology Nurse Specialist and the Patient Involvement Lead from Wessex Cancer Alliance.

  Both partners consistently demonstrated a high level of professionalism and commitment, going above and beyond to ensure that SOS Polonia was well-supported at every stage of the process. Throughout the coordination meetings, all parties engaged actively and constructively. The collaborative atmosphere was characterised by openness, mutual respect, and a willingness to address any questions or uncertainties that arose. This supportive environment significantly contributed to the successful and smooth progression of the project.

What were some of the challenges

- Recruitment of interviewees
- There were challenges to set up and administer thank you vouchers.
  This meant that it felt slow for interviewees.