Integrating the lived experience within the non-surgical oncology advanced practice framework: a pilot study

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Abstract

Oncological services face increasing demand driven by an ageing population, new treatment opportunities, and workforce challenges, which have expanded the roles of nurses, allied health professionals, and pharmacists in the United Kingdom. However, inconsistencies in training, education, and role expectations are evident, highlighting the need for a patient-centred curriculum in non-surgical oncology.

A national framework for advanced practitioners in non-surgical oncology seeks to standardise education and training. This pilot study examines perceptions of those with lived experience on advanced practice and the framework.

Method

A qualitative descriptive approach was used to explore the thoughts and perceptions of individuals with lived experience of healthcare provided by advanced practitioners. The pilot study involved a two-phase design: an initial online questionnaire to gather an overview of the understanding of the role (n=7), followed by an online focus group to examine the framework in more detail (n=4). Descriptive statistical analysis was performed to identify patterns in the data. Ethical approval was granted, and convenience sampling was utilised to collect the data.

Results

Questionnaire and focus group results highlighted the importance of formal introductions, visible advanced practitioners, and the inclusion of patients' voices.

Participants stressed advanced practitioners demonstrating leadership, communication, educational, research, and treatment expertise. They also noted that practitioners' attitudes and behaviours are vital for building trust and confidence in patient care.

Conclusion

The pilot study concluded that individuals with lived experience valued the four pillars of practice and the humanistic behaviours necessary to build confidence and trust in the advanced practitioner. These findings have further influenced and shaped the final version of the non-surgical oncology advanced practice framework.

Keywords:

Curriculum design. Advanced Practice. Lived Experience. Patient and Public Involvement and Engagement.

Background

The oncology workforce faces significant challenges in meeting the increasing demands for cancer care in the UK (Macmillan Cancer Support, 2023). The NHS Long-Term Workforce Plan (2023) emphasises that expanding the roles of experienced healthcare practitioners is key to building capacity and driving innovation. Strategic workforce development in non-surgical oncology (NSO), which uses radiotherapy and/or systemic therapies for cancer treatment, has focused on increasing the skill mix by incorporating advanced practitioners (APs). It should be noted that such roles may also be referred to as Advanced Clinical Practitioner (ACP); however, for consistency within this pilot study, the term AP is used. The four pillars of professional practice are identified as clinical practice, leadership and management, education, and research—a synthesis of these pillars supports the development of the APs across healthcare practice (Clarkson & Dimopoulos, 2025). Access to specific education and training aligned with NSO is lacking nationally, and 'generic' advanced practice (AP) education is being utilised (Clarkson & Khine, 2024). This impacts knowledge development within roles, with practitioners undertaking additional master's modules to meet their specific learning requirements.

The development of an NSO Advanced Practice Framework (NSOAPF) has utilised an iterative, evidence-based approach, with a local evaluation conducted in the North of England (Clarkson et al, 2024) and a national consensus review (Clarkson et al, 2025). The NSOAPF is an area-specific capability framework supporting speciality education and training at this level of practice. At each evaluation stage, the experts (leading advanced practice educators, researchers, consultant oncologists, specialty APs, and AP Leads) within the working party reviewed the NSOAPF and applied the research recommendations. Including those with lived experience of healthcare as

patients or carers in the review of the framework was critical to ensuring the NSOAPF is fit for purpose and to provide education and training with the patient at the heart of its development and implementation (Strudwick et al, 2024).

Osler first suggested including lived experience in formal healthcare education to educators over a hundred years ago (Towle & Godolphin, 2011).

> *'…for the junior student in medicine and surgery, it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself' (Osler, 1904)* (Towle & Godolphin, 2011).

Evolution has seen this philosophy evolve, linked to the World Health Organisation (WHO) paradigm for social accountability, developing healthcare education that meets population needs (Gordon et al., 2020), supporting the development of compassionate practitioners who reflect person-centred care and shared decision-making for modern times (Morgan & Jones, 2009). Variations in terminology used to articulate inclusion include lived experience, patient, public, caregiver, or lay representation (Rowland et al*,* 2019). In this pilot study, the term 'lived experience' will be used. The inclusion of lived experience can be defined across the academic educational process, teaching, assessment and/or curriculum design (Towle & Godolphin, 2011; Jha et al, 2010).

The inclusion of lived experience is believed to have a positive impact, although this is not underpinned by research evidence (Regan de Bere & Nunn, 2016), and often focuses on curriculum delivery rather than curriculum design (Rowland et al*.,* 2019). The drive for increased involvement from those with lived experience is a result of a shift in healthcare education from traditional 'paternal' models to 'patient-centred' models, with the patient at the centre of all learning (Rowland et al*.,* 2019).

Including those with lived experience is commonplace in other areas of healthcare, such as research, where the UK Standards for Public Involvement in Research (National Institute for Health and Care Research, 2019) set the standard. In 2018, the College of Radiographers published *'Patient, public and practitioner partnership within imaging and radiotherapy: guiding principles'* (The College of Radiographers, 2018). With a section dedicated to education, providing the views of the patient in wanting to be involved, *"I might have some very innovative ideas about the things students should be taught based on my experience as a patient or carer that will add another perspective to their course".* Professional, Statutory, and Regulatory Bodies (PRSBs) also expect the inclusion of the lived experience in education and training (Health Care Professions Council, 2025). With further examples in *The Health Foundation Inspiring Improvement Report (2011), can patients be teachers? Involving patients and service users in healthcare professionals' education.* Integrating lived experience into healthcare education may necessitate additional support to enable individuals to share their experiences confidently. There can be challenges in ensuring the group's representativeness, as well as in discussing experiences, their emotional impact, and how they relate to the development of learning outcomes. Creating a supportive environment with appropriate briefing and debriefing allows patients to effectively use their voice, their primary tool, to convey their experiences (Palmaria et al, 2024). Renumeration for the individual with lived experience should also be considered in the briefing and debriefing process. (National Institute for Health and Care Research (2019), The College of Radiographers, 2018).

'The Spectrum of Involvement' (Anderson et al, 2025) is adapted from Towle et al, 'The Ladder of Involvement' (Towle & Godolphin, 2011) (adapted from 'The Ladder of Citizen Participation' Arnstein, 1969), and The Cambridge Framework (Spencer et al,

2000). An example of the inclusion of lived experience can be seen in Figure 1, which is utilised to support the measurement of depth and impact on the education provided. (Towle & Godolphin, 2011)

Evaluating and embedding the perceptions of individuals with lived experience regarding AP and the practitioners who provide their care is crucial to the education and practice of APs. Additionally, these perceptions play a significant role in curriculum design. The aims of this pilot study were:

Critically evaluate the expectations of knowledge, skills and attributes that patients and carers expect of advanced practitioners in non-surgical oncology.

Consider patients' and carers' perceptions of being cared for by an advanced practitioner and how this can positively impact practitioners' education and training.

Method

Study design

A pilot study employing a qualitative descriptive approach was conducted to explore the thoughts and perceptions of individuals with lived experience. This approach enables researchers to investigate the perspectives of those receiving care from APs and utilise this data to influence the development of the NSOAPF. In 2024, a two-phased pilot study was adopted to capture patients' and carers' thoughts and perceptions about being cared for by APs in NSO, their expectations of the knowledge, skills, and attributes required, and how they can positively impact education and training.

Phase one featured an initial online questionnaire created using MS Forms. This

questionnaire consisted of open- and closed-ended questions distributed to all patient networks linked to the NSOAPF working group. After completing the questionnaire, participants were invited to consider joining Phase Two of the project.

Phase two was held one month after the questionnaire closure and involved an online focus group (utilising the MS Teams platform) focused on the NSOAPF to gain further insights into responses to the questionnaire. Participants accessed the documents one week prior to the focus group, allowing them to comment on the content. The questionnaire and focus group questions were derived from the co-authors' previous experience collecting data on patient views. Subsequently, the university's Public Involvement in Research Group (PRIG) reviewed the questions to establish their appropriateness for the pilot study. There was a request to change the term "non-medical practitioner" used to describe the AP, initially chosen due to concerns about potential misunderstanding of the term AP. Although "non-medical practitioner" is a commonly used term nationwide, the PRIG believed it undermined the AP's role by implying that the AP was non-medical. The term "advanced practitioner" was agreed upon by consensus to maintain consistency in clinical practice.

Ethical considerations

Before data collection, potential participants were approached through established Patient and Public Involvement and Engagement (PPIE) networks; therefore, study approval was required only from the University Ethics panel. Those with lived experience who were interested in participating received a participant information sheet in advance, and consent was obtained. Remuneration was also offered to participants.

Recruitment

Challenges arose in accessing appropriate patient and carer groups who could provide

insights into curriculum development; therefore, a convenience sampling approach was employed, although the authors recognised it as a limitation that impacted the generalizability of the results. However, the importance of inclusivity is a key part of this NSOAPF development, and the benefits of the data gathered continue to inform it. Through networking, several patient and carer groups with NSO experience were approached to promote the project and complete phases one (n=7) and two (n=4).

Data collection

The questionnaire included both open- and closed-ended questions to understand participants' initial thoughts and perceptions of APs. A focus group guide (Table 1) guided the discussion, which lasted approximately 45 minutes. With the participants' permission, the focus group was recorded via MS Teams and transcribed verbatim.

Data Analysis

Two project team members (MC, RK) independently reviewed the transcripts. Using Braun and Clarke's approach (Braun & Clarke, 2006). The data were inductively analysed using thematic analysis. Consensus was reached by comparing independent analyses of the themes and resolving any differences through discussion until agreement was achieved, resulting in four themes.

Results

The questionnaire received seven responses (n=7), and four participants (n=4) accepted the focus group invitation.

Phase 1 Questionnaire:

The questionnaire provided an essential overview of the perceptions of AP, with most participants happy to be cared for by an APs:

"I would, but I would hope that a medical doctor would supervise the practitioner."

" Yes - where professional expertise is guaranteed and appropriate to function."

Furthermore, whilst participants were supportive of being cared for by an APs, they highlighted that knowing the identity and background of the AP was an important aspect, specifically referencing formal introductions and their visibility in a clinical setting:

"Full name and their background - assure me they are not a [medic] but will give me the best care"

"A different uniform would help to identify them, for example, the same as different hospital uniforms. Their ID badge should also identify their role. Photo boards can also provide patients with a better understanding"

Interestingly, a minority of participants expressed views linked to the recent debate over the role of the physician associate in healthcare.

"However, I wish not to be seen by a physician associate as I believe their training is inadequate and their regulation is not fit for purpose."

The questionnaire also highlighted participants' views on the importance of education and training for APs, particularly concerning the four pillars of practice. From the questionnaire, participants identified the skills they felt APs needed to demonstrate, including *advanced leadership, advanced communication, advanced research skills* and *expert knowledge of their treatment*. In addition, participants communicated that such roles should have the expected high standard of education and training:

"They should have regular reviews and updates of knowledge and training. Evidence of previous experience, ongoing professional development, and supervision"

Phase 2 Focus group:

Four discrete themes were identified from the focus group: the patient voice; attitudes and behaviours of APs; Education and training and expectations of APs; and the four pillars of practice.

Participants felt that the inclusion of the patient's voice in the curriculum development was crucial and needed to be explicit throughout the document:

"In my view, the patient perspective is needed".

"You know, making the service user voice or the patient perspective or service user perspective more integral"

Moreover, participants positively acknowledged that the curriculum documents demonstrated the necessary characteristics to be an AP, highlighting the importance of exhibiting these to provide patients with assurance for the role:

"The documents tease the required skills, knowledge, experience, attitudes, and behaviours. I think attitudes and behaviour are critical. As a patient, I [need to] have confidence in that individual's knowledge, skills, experience, and behaviours."

Participants were keen to voice their views surrounding the training of APs and the quality and standard of education and training as reflected in the documentation:

"I'll just say the capabilities in practice, these CiPs are an excellent high-level indicator of the learning outcomes to achieve at the training."

"I think one of the important tasks for yourselves is to make sure that the standards are indeed high enough and represent all those functions they carry out."

Yet alongside the education and training, participants also highlighted that the documents provided clear expectations regarding the AP role for both the trainee and those supporting the role:

"I particularly liked both documents in that they gave a clear steer on what this is about and a clear steer about many of the expectations."

"The robustness and high expectations on the part of the assessors and indeed those who go into the scheme, I think, are crucial."

Finally, all participants agreed that the four pillars of practice must be embedded in the

curriculum and a primary feature of the role.

“I think all four are needed, and they make up what is required actually to be called and passed to be an advanced practitioner”

“I think that they're all of equal importance, and I think you've got to have some foundations with which to get these people actually to be advanced practitioners”

Discussion

This element of the development of the NSOAPF has demonstrated the critical role that patients and service users play in informing the education and training of APs. The focus group responses acknowledged the perceived benefits of their involvement, such as providing a unique perspective and insight into their personal experiences, as well as offering an opportunity to influence learning and development. The *Spectrum of Involvement* application should consider the risks of power imbalance and relationship disruption between those with lived experience and healthcare educators (Rowland et al*.,* 2019). It should be acknowledged that although the individual with lived experience is an expert on the care received, they are not the expert on the underpinning knowledge required to develop competency and capability to provide care safely (Jha et al, 2010). Involving those with lived experience in healthcare education is now a central feature amongst many disciplines, with added benefits (Health Care Professions Council, 2025). However, they should be seen as direct partners in healthcare education, not as ‘objects for students to learn from’ (Rowland et al., 2019), but rather as complements to educators' professional knowledge (Jha et al., 2010). They should be involved in all stages of learning, steer curriculum design and assessment, and even be members of the programme development team (Strudwick et al., 2024; The College of Radiographers, 2018). With recommendations by Professional, Statutory, and Regulatory Bodies that *“service users and carers must*

be involved" in education programme development (Health Care Professions Council, 2025).

The questionnaire analysis indicated that, within this sample, participants demonstrated a good understanding of the AP role and expressed support for its contribution to the healthcare service. However, the provision of care by an AP's should consider two essential aspects: the AP's professional identity and a robust education and training process. The conflation of the physician associate and AP's identities by the patient participants was important and underlines the confusion that they may have regarding the plethora of roles within the healthcare setting. Communicating APs' identities and roles through simple introductions (such as name and role) is essential for those with lived experience, especially when they are being cared for by APs. Not only is this a fundamental step in patient-centred care, but it also instantly fosters trust and confidence while receiving care (The College of Radiographers, 2025; Granger K, 2013). Additional visibility could reinforce this message through other media, such as a name badge or a designated uniform.

Appropriate education and training requirements for AP roles were seen as critical. The multi-professional advanced practice framework (NHS England, 2025) was developed to provide a comprehensive structure and focus for education and training for traditional advanced-level practice roles. However, its application for a specialism is more challenging. Nonetheless, AP roles must be underpinned by education and training that build on the 'root' profession skills, with the opportunity to specialise accordingly (Clarkson & Khine, 2024). In this instance, the availability of the NSOAPF is the first step to formalising education and training within this specialism.

The focus group further reinforced the issues raised in the national consensus (Clarkson et al, 2025). Naturally, there was a strong consensus that AP education and

training must be of a high standard and ensure that the four pillars of practice are consistently demonstrated. Educating and training APs within their specialist or broad practice area typically relies on a solid base of knowledge, skills, and expertise, along with the expectation of holding an accredited master's-level qualification specific to AP (NHS England, 2025). The education and training curriculum should comprehensively cover the necessary knowledge, skills, and behaviours, allowing APs to meet the four pillars of practice (The College of Radiographers, 2022). However, time allocation in job plans can be challenging, and APs' confidence, especially in interpreting the research pillar, can be lacking (Fothergill et al., 2022), leading to reported inconsistencies in meeting AP standards (Woznitza, et al, 2021). Therefore, clarity about the importance and the holistic application of all four pillars is crucial, helping APs and employers allocate adequate resources to engage with all aspects of practice.

Whilst participants agreed that knowledge and skills of APs were essential and were a priority for the working group, they were eager to acknowledge that the humanistic aspect of the role, as demonstrated through attitudes and behaviours, were equally important qualities. High-quality, compassionate patient care is paramount for all healthcare practitioners (Taylor et al, 2021). Equally, mutual trust should exist between patients and all healthcare professionals (Beardmore et al., 2024). Whilst there is growing evidence that AP roles enhance patient satisfaction and positively impact the overall quality of care through effective decision-making (Oliveira et al., 2022; Oliveira et al., 2023).

As a pilot study, the methodology has been tested to assess its feasibility. The authors will build on the foundations of this pilot study to further review the inclusion of the lived experience as the NSOAPF is implemented in the coming years.

Limitations

While the pilot study is subject to sampling limitations—such as potential selection bias and constraints on the generalisability of findings—it nonetheless provides valuable and credible insights from individuals with lived experience of healthcare. These perspectives contribute to the evolving discussion on the education and training of AP roles, highlighting priorities and areas for refinement that may otherwise be overlooked. Importantly, the feedback obtained serves as a critical source of evidence and a constructive driver for the continued development and contextual relevance of the NSOAPF, ensuring it is informed by those directly impacted by healthcare delivery.

Conclusion

This pilot study has identified that including lived experience in curriculum development is increasingly recognised as best practice across all professional, vocational, public and industry-focused organisations. In designing an NSOAPF, the lived experience has been highly valuable, providing multiple perspectives and insights through participants' perceptions and experiences.

Overall, the knowledge, skills, and attributes are essential to ensure AP's capability to provide effective and efficient care. The development across the four pillars at an advanced level of practice was deemed an expectation by the participants. Although it can be challenging, it was valued as part of the broader role of the AP. Further socialisation of the holistic synthesis of the four pillars and their application in practice will further support the AP. The attitudes and behaviours are a priority for those with lived experience, who trust the AP to advocate for and deliver their care. The humanistic attributes are developed through academic and experiential learning, with the patient's assessment of the AP now included in workplace-based assessments.

As the NSOAPF is implemented in practice, ongoing research into its implementation is crucial for assessing its impact on patient satisfaction and cost-effectiveness, and for further informing future research priorities.

To conclude, demonstrating the equal importance of all four pillars and evidencing the required knowledge, skills, attitudes, and behaviours is considered integral to curriculum development, practical implementation, and overall education and training of AP in NSO. The NSOAPF working party successfully applied the feedback on the documents, ensuring patient focus was explicit throughout, and will continue to investigate its application when implemented.

Implications for Practice

The importance of the patient story in advanced practice education is crucial to learners' understanding of how to apply their practice. However, there is a broader opportunity to include patient and public voices in recruitment and curriculum design. The patient is an expert by experience, and their expertise should be widely utilised to enable impactful education and training for advanced practitioners.

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