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

CLARKSON, Melanie <http://orcid.org/0000-0003-3052-5230> and KHINE, Ricardo

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ABSTRACT

Background: 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 UK. However, inconsistencies in training, education and role expectations are evident, highlighting the need for a patient-centred curriculum in non-surgical oncology. **Aims:** This pilot study explored the perceptions of individuals with lived experience of receiving care from advanced practitioners to influence the development of the national non-surgical oncology advanced practice framework to standardise education and training. **Methods:** A qualitative descriptive approach was used for the two-phase study design. An initial online questionnaire gathered 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 data. Ethical approval was granted by the university, and convenience sampling was used to collect data. **Results:** Responses highlighted the importance of formal introductions, advanced practitioners' visibility and the inclusion of patients' voices. Participants stressed the need for advanced practitioners to demonstrate leadership, communication, educational, research and treatment expertise. They also noted that practitioners' attitudes and behaviours were vital for building trust and confidence in patient care. **Conclusions:** Individuals with lived experience valued the four pillars of practice and the humanistic behaviours necessary to build confidence and trust in the advanced practitioner. **Implications for practice:** These findings will further influence and shape the final version of the non-surgical oncology advanced practice framework, developed by a team led by the lead author.

Key words
advanced practice, curriculum design, lived experience, patient and public involvement and engagement

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Melanie Clarkson
BSc (Hons), PGCE, MSc, PFHEA, Sheffield Hallam University, Sheffield, UK
m.clarkson@shu.ac.uk

Ricardo Khine
FCR, PhD, MA, BSc (Hons), SFHEA, MAcadMEd, Queen Mary University of London, UK

The oncology workforce faces significant challenges in meeting the increasing demands for cancer care in the UK (Macmillan Cancer Support, 2023). The NHS England (2023) long-term workforce plan has emphasised 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). Such roles may also be referred to as advanced clinical practitioners, but for consistency within this pilot study, the term AP is used.

Access to specific education and training aligned with NSO is lacking nationally, with generic advanced practice education being used (Clarkson and Khine, 2024). This affects knowledge development within roles, often requiring practitioners to undertake additional Master's modules to meet their specific learning requirements.

To address this, the development of the NSO Advanced Practice Framework (NSOAPF), led by the lead author (MC), followed an iterative, evidence-based approach, including a local evaluation in the North of England (Clarkson et al, 2024) and a national consensus review (Clarkson et al, 2025).

The NSOAPF provides an area-specific capability framework to support speciality education and training at this level of practice. At each stage, experts, including leading advanced practice educators, researchers, consultant oncologists, specialty APs and advanced practice leads, reviewed the framework and applied research recommendations. The inclusion of those with lived experience of healthcare as patients or carers in these reviews ensured that the NSOAPF remained fit for purpose and patient-centred (Strudwick et al, 2024).

Terminology for inclusion varies, encompassing lived experience, patient, public, caregiver or lay representation (Rowland et al, 2019). In the present study, the term 'lived experience' is used.

Inclusion of lived experience can occur across the academic educational process, including teaching, assessment and curriculum design (Jha et al, 2010; Towle and Godolphin, 2011). Although evidence on the impact of lived experience is limited (Regan de Bere and Nunn, 2016), its inclusion is increasingly advocated, particularly in curriculum design rather than solely delivery (Rowland et al, 2019). This shift reflects a broader movement in healthcare education from traditional 'paternal' models to patient-centred

approaches, placing patients at the heart of learning (Rowland et al, 2019).

Including lived experience is common in other areas of healthcare, such as research, where the UK Standards for Public Involvement in Research set expectations (National Institute for Health and Care Research (NIHR), 2019). Regulatory and professional bodies also expect this inclusion in education and training (Health Care Professions Council, 2025). For example, the College of Radiographers (2018) highlighted patients' contributions in education, noting that patients may offer innovative ideas on course content based on their experiences.

Integrating lived experience effectively may require additional support, such as briefing and debriefing, to enable individuals to share experiences confidently, address emotional impacts and ensure representativeness. Consideration of remuneration for participants is also recommended (College of Radiographers, 2018; NIHR, 2019; Palmaria et al, 2024).

The spectrum of involvement (Anderson et al, 2025), adapted from Towle and Godolphin's (2011) ladder of involvement (Arnstein, 1969) and the Cambridge Framework (Spencer et al, 2000), illustrates how lived experience can be integrated into education. *Figure 1* demonstrates its application in measuring the depth and impact of involvement on the education provided.

Evaluating and embedding the perspectives of individuals with lived experience regarding APs and the care they receive is crucial for curriculum design, education and practice within NSO.

Aims

The aims of this pilot study were to:

- Critically evaluate the expectations of knowledge, skills and attributes that patients and carers expect of APs in NSO
- Explore patients' and carers' perceptions of being cared for by an AP and how this can positively impact practitioners' education and training.

Methods

Study design

A pilot study using a qualitative descriptive approach was conducted to explore the thoughts and perceptions of individuals with lived experience of receiving care from APs. This approach enabled the researchers to study the perspectives of those receiving care from APs and use these data to influence the development of the NSOAPF. This two-phased pilot study was conducted in March to May 2024 to explore 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 1 featured an initial online questionnaire created using Microsoft 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 2 of the project.

Figure1. Examples of patient/community roles in health professional education along a spectrum of involvement (Towle and Godolphin, 2011).

Phase 2 was held in May 2024, 1 month after the questionnaire closed, and involved an online focus group (using Microsoft Teams) centred around the NSOAPF to gain further insights into responses to the questionnaire. Participants were able to access the documents 1 week before the focus group and comment on the content.

The questionnaire and focus group questions were derived from the co-authors' previous experience of collecting data on patient views. Subsequently, the Sheffield Hallam University Public Involvement in Research Group reviewed the questions to establish their appropriateness for the pilot study. They requested to change the term 'non-medical practitioner' used to describe the AP, initially chosen because of concerns about potential misunderstanding of the term AP. Although 'non-medical practitioner' is a commonly used term nationwide, the Public Involvement in Research Group believed it undermined the AP's role by implying that the role was non-medical. The term 'advanced practitioner' was agreed on 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 networks. Therefore, study approval was required only from Sheffield Hallam University's ethics panel. Those with lived experience, who were interested in participating, received a participant information sheet in advance, and written consent was obtained. Remuneration was also offered to the participants pro rata, in line with NIHR guidance.

Recruitment

The team faced challenges in accessing appropriate patient and carer groups who could provide insights into curriculum development. Owing to the increase in requests for involvement of those with lived experience, groups can feel overwhelmed by the volume, especially when a request is more complex, such as a curriculum review. Therefore, a convenience sampling approach was used, although the authors recognised it as a limitation that impacted the generalisability of the results. However, inclusivity remains a central principle in the development of the NSOAPF, with insights from the data continually informing its refinement. Through networking, several patient and carer groups with NSO experience were approached to promote the project and complete phases 1 (n=7) and 2 (n=4).

Data collection

The questionnaire included eight questions: one open-ended and seven closed-ended. The closed-ended questions required respondents to rank a set of statements. The aim was 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 Microsoft Teams and transcribed verbatim.

Data analysis

Two project team members (MC and RK) independently reviewed the transcripts using Braun and Clarke's (2006) approach. 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.

Results

The questionnaire received seven responses, and four participants 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 AP:

> *'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, while 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. Their ID badge should also identify their role. Photo boards can also provide patients with a better understanding.'*

A minority of participants expressed views linked to the 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*

Table 1. Focus group question guide

Open discussion about the documents
What experience do you have of being cared for by advanced practitioners?
What skill set would you expect advanced practitioners to possess?
What challenges do you foresee for the trainee advanced practitioner, supervisor and/or service?
What benefits do you foresee for the trainee advanced practitioner, supervisor and/or service?
This discussion is very clinically focused but advanced practitioners must demonstrate clinical, leadership, education and research capabilities. How do you think they may achieve this?

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.'

'...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 characteristics necessary 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 capabilities in practice 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.'

However, 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 APs.'

Discussion

The development of the NSOAPF has demonstrated the critical role that patients and service users play in informing the education and training of APs. Focus group responses highlighted the perceived benefits of involving those with lived experience, including providing unique insights and influencing learning and development. However, the application of the spectrum of involvement must consider risks, such as power imbalances and relationship disruption with educators (Rowland et al, 2019).

While individuals with lived experience are experts in the care received, they are not experts in the underpinning knowledge required to develop competency and capability safely (Jha et al, 2010). They should be engaged as direct partners in education, complementing professional knowledge and involved in all stages of learning, curriculum design, assessment and programme development (College of Radiographers, 2018; Strudwick et al, 2024; Health Care Professions Council, 2025).

Questionnaire analysis indicated that participants understood the AP role and supported its contribution to healthcare. However, care delivery must consider the APs' professional identity and robust training. Confusion between physician associates and APs highlights the need for clear communication of role identity, including simple introductions, name badges or designated uniforms to foster trust and patient-centred care (Granger, 2013; College of Radiographers, 2025).

Education and training were identified as critical, with the multi-professional advanced practice framework providing a comprehensive structure for traditional roles (NHS England, 2025). Specialisms, such as NSO, require tailored application. AP roles should build on root-profession skills and allow for specialisation, with the NSOAPF providing the first formalised education and training pathway (Clarkson and Khine, 2024).

Focus group discussions reinforced national consensus that AP education must ensure mastery of the four pillars of practice, reinforced by accredited Master's-level training, despite challenges in job plan allocation and confidence in research skills (Woznitza et al, 2021; Fothergill et al, 2022; Clarkson and Dimopoulos, 2025). Clarity on all four pillars is essential to support both APs and employers in allocating resources for holistic practice.

Participants emphasised that knowledge and skills were essential, but humanistic qualities demonstrated through attitudes, behaviours, compassion and mutual trust were equally important in high-quality patient care (Taylor et al, 2021; Beardmore et al, 2024). Growing evidence suggests that AP roles enrich patient satisfaction and overall care quality through effective decision making (Oliveira et al, 2022; 2023).

As a pilot study, this methodology demonstrates feasibility. The findings will inform ongoing evaluation of lived experience inclusion as the NSOAPF is implemented in the coming years.

Limitations and strengths

While the pilot study was subject to sampling limitations, such as potential selection bias and constraints on the generalisability of findings, it provided valuable and credible insights from individuals with lived experience of healthcare. These perspectives will contribute to the evolving discussion on the education and training of AP roles, highlighting

KEY POINTS

- Patients value the inclusion of the four pillars in the role of the advanced practitioner
- Patients would like to be involved in the recruitment, learning, teaching and assessment of advanced practitioners
- The humanistic behaviours of advanced practitioners are key to a patient having a positive experience
- The lived experience can be used throughout the spectrum of involvement, not just the sharing of experience.
- The well-being of practitioners throughout training is a key priority for everyone involved in developing advanced practitioners.

CPD reflective questions

- How can advanced practice training be improved to better align with patient expectations and experiences?
- What aspects of advanced practice training are most visible or meaningful to patients?
- How can you include patients in your training or the training of advanced practitioners?

priorities and areas for refinement that may otherwise be overlooked.

Implications for practice

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

Conclusions

The feedback obtained through this study serves as a critical source of evidence and a constructive driver for the continued development and contextual relevance of the NSOAPF, ensuring that it is informed by those directly impacted by healthcare delivery.

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. During the design of the NSOAPF, lived experience has been highly valuable, providing multiple perspectives and insights through participants' perceptions and experiences.

Overall, 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.

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 to the framework and supporting documents, making them more explicitly patient-focused throughout and suggesting how patients can be involved in the recruitment and assessment of the AP, not just by sharing their stories for learning. As part of the implementation phase the working party will continue to evaluate the application of the lived experience throughout the whole educational process. IJAP

Ethical approval: *Before data collection, potential participants were approached through established Patient and Public Involvement and Engagement networks, therefore, study approval was required only from Sheffield Hallam University's ethics panel.*

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