



Credit: Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

Key points

- ILDs are often complex and associated with significant mortality, morbidity and co-morbid conditions that require a technical healthcare skill set
- There is worldwide shortage of nurses, low retention rates and retirement of many skilled nurses
- Collaboration across the ILD interdisciplinary community is needed to safeguard the future of our professions and high-quality patient care
- The ILD interdisciplinary and nurse network has identified key priorities to help secure the future of the ILD clinical and academic nurse specialism

Educational aims

- To explain the similarities and differences between clinical nurse specialists (CNSs) and advanced nurse practitioners (ANPs) in the context of ILD specialism
- To review contemporary nursing specialism in the UK's government subsidised healthcare system
- To stimulate discussion and debate across the European/international respiratory community regarding the clinical and academic development of the ILD CNS
- To identify key priorities that will support collaboration across the ILD interdisciplinary workforce in clinical practice and research



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Contemporary challenges for specialist nursing in interstitial lung disease

The role of clinical nurse specialists (CNSs) in interstitial lung disease (ILD) is evolving in response to clinical guidelines and the growth of clinical research. The role is well established in the UK, although more ILD posts are needed to ensure supply meets clinical demand. This phenomenon is also happening across Europe. An appreciation of the similarities and differences between CNS and advanced nurse practitioners is important given the challenges in defining, developing and supporting this nursing specialisation. Globally, different models exist. In some countries charitable organisations take a leading role in supporting patients. Many European centres look to the National Institute for Health and Care Excellence guidelines and quality standards as a template to develop and evaluate the role of the ILD CNS. We present a UK perspective in the context of a government subsidised healthcare system to promote professional discussion and debate regarding the future of nursing practice in the ILD specialty.

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Specialist nurses and interdisciplinary healthcare professionals are fundamental to the care of patients diagnosed with ILD. ILD specific clinical and academic standards are needed to sustain and develop a dedicated ILD workforce <http://ow.ly/toee30h1UKW>

The interstitial lung disease clinical nurse specialist

Interstitial lung diseases (ILDs) are associated with fibrotic changes in the interstitium of the lung [1]. Whilst some forms of ILD are short lived, many are irreversible. ILDs are associated with high morbidity and mortality, particularly idiopathic pulmonary fibrosis (IPF) an interstitial pneumonia of unknown cause.

Symptom management and palliative care are the hallmarks of ILD clinical nurse specialist (CNS) management. The key focus is on assessing and managing breathlessness, fatigue, cough and psychological distress. The plan of care requires

frequent adjustment as the condition progresses, particularly after an exacerbation or “flare”. Emphasis is on empowering patients to self-care in the context of their family.

Nurses are considered to be central to healthcare provision and highly valued by patients particularly in the ILD specialism [2–5]. The ILD CNS plays a key role in coordinating care and liaising with the multidisciplinary and interdisciplinary teams. In the UK, 90% of patients reported that an ILD specialist nurse was their main clinical contact for IPF healthcare [4]. The CNS provides expert knowledge and advice to patients, their families and carers, throughout all stages of their care [4, 5]. This includes lifestyle advice, access to and management of oxygen, and medication including management



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of adverse side-effects and signposting to patient support organisations. CNSs are often required to discuss complex test results, treatment options and other concerns that the patient and/or their family may raise. Given the complexity of ILD it is not surprising that patients express a need to have 3-monthly contact with their CNS [6]. Many patients also have comorbidities which require additional generic clinical knowledge.

The National Institute for Health and Care Excellence (NICE) published a quality statement in 2015 recommending that minimally “People with idiopathic pulmonary fibrosis have an ILD specialist nurse available to them” [7]. The rationale for this is that “An ILD specialist nurse can ensure that people with idiopathic pulmonary fibrosis, and their families and carers, receive all the information and support they need throughout the care pathway ... specialist nurses can sensitively discuss prognosis, disease severity and progression, and life expectancy” [7].

This quality standard is supported by the IPF NICE guidelines [8]. It requires commissioners (NHS England specialised services area teams) to ensure that commissioned services employ an ILD CNS as part of their multidisciplinary team.

However, there is some evidence of disparity in healthcare provision. A UK national patient survey of 122 patient and carer respondents from the British Lung Foundation reported that only 39% of patients have frequent contact with an ILD specialist nurse, 36% of patients say they have no access at all and only eight UK trusts routinely allocated patients a named ILD specialist nurse within 6 months of diagnosis [2].

These findings are supported by Action for Pulmonary Fibrosis [3] who further report that 60% of patients surveyed consider the ILD CNS as the best single point of contact for their care. More recently the British Lung Foundation have highlighted that “more specialist nurses with ILD training and expertise are still needed” [9].

Specialist centres are being developed across the UK and Europe creating a greater need for ILD CNSs. Given the limited number of experienced well-trained ILD CNS already established in practice and the lack of robust accredited training course, many nurses will most likely require “on the job” training in the short term. This compounds existing issues of standardisation of nursing roles that can inform clear pathways of professional development and advancement of careers.

Expansion of nursing practice

In 2002 a UK government paper offered new opportunities to develop advanced and specialist nursing roles [10]. It promised greater freedom to innovate and make decisions about the services and care provided, for nurses to become effective leaders and to take on new roles and ways of working to deliver improvements for patients and

communities. Autonomous practice was promoted, matching accountability with individual professional judgment. This was reinforced by the modernising nursing careers initiative received with enthusiasm by the nursing community [11].

Nursing roles have progressively expanded and diversified in the ensuing 15 years, partly in response to the increasing demands on healthcare services. The political drivers have remained consistent: to improve healthcare quality and efficiency in service delivery [12]. Changes to the training and roles of junior doctors have impacted on nursing, so that nursing roles may have developed to plug gaps in the healthcare system rather than advance nursing skills *per se*. CNS and advanced nurse practitioners (ANP) roles emerged but without standardisation in the UK and Europe, giving rise to confusion amongst professionals and patients [13–15]. ANPs were perceived as delivering a higher level of care at a strategic level whilst clinical specialists rated higher for continuity of care and carer [16].

Critical thinking, an ability to work strategically and continuity of care are prerequisites for the ILD CNS thereby incorporating elements of advanced practice implying that this is a hybrid role. There are some differences in the academic training of the CNS and ANP (table 1) whilst both ANPs and many CNS practice autonomously in the UK. This raises two important questions: 1) how do we develop and support a specialist nursing team fit for the future?; 2) how do we deliver the standardised high-quality care that patients should expect?

UK case study

In the UK, agenda for change was introduced in 2004. Its aim was to harmonise pay scales and career progression for nurses and NHS staff, with the exception of doctors, dentists and some senior managers. The agenda for change system allocates the post to a set pay band based on the skills required for the job. The Knowledge and Skills Framework, a competency-based framework for job evaluation, is integral to the agenda for change system [18]. Staff are matched to a job profile and corresponding pay band [19]. It was perhaps perceived as a way to standardise practice and the plethora of professional titles that exist; however, this has not been the case. Whilst agenda for change is designed to evaluate the job irrespective of the individual's strengths, this approach to standardisation has given rise to depersonalisation. The rationale was commendable; to ensure equity between similar posts in different geographical areas. However, the depersonalising of roles risks the skill set of the individual not being appropriately rewarded. As an individual develops their scope of practice, financial remuneration may not keep pace and may negatively impact on staff morale.

Progression up the agenda for change scale will require a re-grading of the post which

Table 1 Attributes of specialist nurse and advanced nurse practitioners

	Specialist nursing practice		Advanced nursing practice	
	Essential	Additional	Essential	Additional
Experience		Long-term clinical experience		Long-term clinical experience
Qualifications	Qualification in specialist field (BSc)	MA/MSc	MA/MSc	Qualification in specialist field
Role functions	Prescribing Linking with other agencies/coordination Research Quality improvement	Diagnosing Assessing Leadership management Teaching Education	Autonomous practice Diagnosing/assessing/physical examination/admitting Prescribing Leadership/management Staff development/supervision Research Quality improvement Promote evidence-based practice Teaching/education	Inter-professional working
Additional nursing competences	Advanced communication skills		Advanced communication skills	Critical appraisal

Reproduced from [17].

requires substantial change to the job description, including the role and responsibilities through detailed in-house assessment. This is because the structure is focussed on the position not the person. It does not reward the development of professional skill, clinical experience and increased level of responsibilities beyond the scope of the post. An individual's professional development beyond this scope would not be regarded as sufficient for re-grading that post. This can be perceived as a barrier to career progression for nurses, pharmacists and allied health professionals, and may also impact retention of staff.

Given the mortality, morbidity, co-morbidities and complexities associated with ILDs, nursing staff require a technical skill set in-keeping with Masters level (critical) thinking [20]. The ILD CNS role thus appears to be even more closely aligned with advanced level nursing practice.

An ILD CNS working to the principles of advanced practice should be commensurate with the band 7 grading on agenda for change. To progress to agenda for change band 8 Masters level study is essential (table 1) with capacity for doctoral level study. However, informal clinical conversations suggest that lower pay bands (by implication lower skill levels) are often applied to respiratory CNS roles, particularly those without Master's qualifications.

In the UK some CNSs undertake additional training in non-medical prescribing. There are now drivers to ensure that undergraduate nurse training programmes prepare nurses for non-medical prescribing practice to embed these skills as usual practice.

All nursing posts in the UK have to fit within the Knowledge and Skills Framework while core standards for CNS and ANP roles are set by the Nursing and Midwifery Council, the UK regulatory body [17]. The Nursing and Midwifery Council do not regulate the use of ANP or CNS titles, therefore, standardisation of roles is lacking; a state that has been challenged by the Royal College of Nursing [21] and the International Council of Nurses [22]. A lack of regulation contributes to inconsistencies in the scope of practice, barriers to career progression and inadequate provision of education [20, 23, 24].

Currently only specialist community public health nurses and nurses holding a specialist practice qualifications, *i.e.* general practice, mental health, children's nursing, learning disability nursing and district nursing, are recorded as specialists on the Nursing and Midwifery Council professional register. ANPs in the UK can now apply for accreditation under a new scheme developed by the Royal College of Nursing. Credentialing allows nurses to gain formal recognition of their level of expertise and skill in their clinical practice, leadership, education and research in a way that is recognisable to colleagues, employers, patients and the public [25]. This promotes credibility and standardisation and offers a model that the CNS may wish to emulate.

Education

The Royal College of Nursing apply the International Council of Nurses definition of ANP to promote a

degree of common understanding and a foundation upon which to develop nursing roles: "An ANP is a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and country in which s/he is credentialed to practice. A master's degree is recommended for entry level" [22].

This aligns with the attributes of many ILD CNS working within the UK. ANPs and CNSs in the USA typically hold a master's degree although only 16 states support autonomous practice [23]. The development of nursing practice differs from country to country pan Europe. In the UK, the Royal College of Nursing accredits and validates programmes of ANP study, progressively offered only at Master's level, that meet the 15 Royal College of Nursing standards. These include the policies, practices, curriculum, resources, and research and development of the Higher Education Institution [20]. ANPs typically undertake additional training in non-medical prescribing. CNSs in the UK may complete Master's level study relating to their specialism, *e.g.* MSc in cardiorespiratory nursing. Such programmes focus on clinical nursing practice, care and programme management, clinical practice development and clinical practice leadership with elements of research practice. An educational charity within the UK offers a postgraduate module in ILD which is delivered using blended learning, predominantly online learning. This is accredited at Masters level by a UK university.

Discussion

It is established that patients and carers value having access to an ILD nurse specialist [2–4]. NICE guidelines recommend that the ILD CNS is embedded within specialist teams [1]. However, in this context the nurse *per se* can be professionally isolated. ILD nursing requires technical knowledge at the diagnostic stage and compassionate communication skills. Nurse specialists trained in non-medical prescribing manage additional demands relating to restricted eligibility to specialist drugs. Pharmacological interventions in ILD are commonly associated with a challenging side-effect profile and most non-pharmacological approaches lack a robust evidence base. ILD nurses play an important role in anticipatory prescribing and supporting the patient through the various transitions along the pathway of care. Therefore, the ILD CNS must be particularly skilled in critical thinking, shared decision making and managing uncertainty, particularly when a definitive diagnosis is not possible and the treatment pathway unclear.

For many, the role of the ILD CNS is part time within a wider role. There is risk of burnout given

the high mortality associated with ILDs. Senior ILD nurse specialists struggle to meet the gap of providing clinical supervision and mentorship. Yet, they remain committed to delivering high-quality ILD services. To ensure these are sustainable many ILD CNS are involved in developing business cases to justify their own roles and ensure remuneration is commensurate with their skill set within agenda for change constraints in the UK.

It is challenging to develop the profession when the NHS is running at a deficit. CNS posts were drastically reduced in the NHS deficits crisis of 2005/2006 and there is concern that many CNS will be redeployed or downgraded in response to continuing economic challenges. Reducing the ILD CNS workforce would be at odds with NICE ILD guidelines and impact patient care [2].

A worldwide shortage of nurses was described as a global crisis less than a decade ago and many of the highly skilled nurses will retire in the next 15 years [26]. There is an urgent need to harness the expertise of these experienced nurses to support the future generation of nurses. Mentoring is invaluable to meet the challenges of demanding clinical roles in the NHS, particular whilst also making a high-level contribution to education and/or research [27].

Responding to the contemporary political climate and NICE guidelines and quality standards we established a not-for-profit ILD interdisciplinary and nurse network in 2015, which aims to: provide support and mentorship; promote ILD specialist clinical practice through education; provide research and professional development; and to influence policy associated with ILD care. Investment in ILD nursing and the interdisciplinary professions will improve patient care at all stages of the care pathway particularly in these rare ILD entities.

The ILD interdisciplinary and nurse network has identified key priorities to secure the future of the ILD clinical and academic nurse specialism: 1) develop sustainable high-quality standardised training in ILD; 2) provide a forum to share best practice; 3) lobby for all ILD CNS to be remunerated at agenda for change band 7 in the UK ensuring equity across this specialism; 4) strengthen the interdisciplinary approach through joint working and research; and 5) invest in mentorship, such as supporting the new ILD interdisciplinary workforce, retaining the existing highly skilled workforce and developing research skills.

Nurse and interdisciplinary-led research makes important contributions to the evidence base of clinical practice particularly in non-pharmacological approaches to symptom management. Through collaborative working we aspire to make a positive difference both to the professions we represent and to patient care. For further information on the network can be found at <https://ild-inn.org.uk>

Conflict of interest

Disclosures can be found alongside this article at breath.ersjournals.com

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References

- Russell AM. Interstitial lung diseases. In: Preston W, Kelly C, eds. *Respiratory Nursing at a Glance*. Wiley-Blackwell, New Jersey, 2016; pp. 68–69.
- British Lung Foundation. Lost in the system. IPF: the patient experience in England. www.blf.org.uk/sites/default/files/BLF-IPF-Report-2015---Lost-in-the-System---250215.pdf Date last accessed: June 10, 2017.
- Action for Pulmonary Fibrosis. Working together: delivering a better future for patients with IPF. www.actionpulmonaryfibrosis.org/wp-content/uploads/2015/10/APF-IPF-Patient-Survey-Report-full.pdf Date last updated: September 2015. Date last accessed: June 20, 2017.
- Russell AM, Ripamonti, E Vancheri, C. Qualitative European survey of patients with idiopathic pulmonary fibrosis: patients' perspectives of the disease and treatment. *BMC Pulm Med* 2016; 16: 10.
- Duck A, Spencer LG, Bailey S, et al. Perceptions, experiences and needs of patients with idiopathic pulmonary fibrosis. *J Adv Nurs* 2015; 71: 1055–1065.
- Burge G, Moore V. The value of a specialist nurse-lead interstitial lung disease clinic, patients' views. *Eur Respir J* 2015; 46: Suppl. 59, PA332.
- National Institute of Health and Care Excellence. Idiopathic pulmonary fibrosis in adults: diagnosis and management. www.nice.org.uk/guidance/cg163 Date last updated: May 2017. Date last accessed: June 20, 2017.
- National Institute of Health and Care Excellence. Idiopathic pulmonary fibrosis in adults. www.nice.org.uk/guidance/qs79 Date last updated: January 2015; date last accessed: January 05, 2018.
- British Lung Foundation. A map for better care: making effective care pathways for people with interstitial lung disease. https://cdn.shopify.com/s/files/1/0221/4446/files/BLF_ILD_Report_FINAL_web.pdf?1632606191358891026&_ga=2.144935792.532536784.1512640235-1828180522.1512640235 Date last updated: September 2017; date last accessed: January 05, 2018.
- Department of Health. Liberating the talents: helping primary care trusts and nurses to deliver the NHS plan. http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007473 Date last updated: 2002.
- Department of Health. Modernising nursing careers: setting the direction. http://webarchive.nationalarchives.gov.uk/20071104154823/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138756 Date last updated: 2006; date last accessed: January 05, 2018.
- Hoare KJ, Mills J, Francis, K. The role of Government policy in supporting nurse-led care in general practice in the United Kingdom, New Zealand and Australia: an adapted realist review. *J Adv Nurs* 2012; 68: 963–980.
- Waters A. A role under scrutiny. *Nurs Stand* 2011; 25: 18–20.
- Donald F, Bryant-Lukosius D, Martin-Misener R, et al. A clinical nurse specialists and nurse practitioners: title confusion and lack of role clarity nursing leadership. *Nurse Leadership* 2010; 23: 189–210.
- Nursing and Midwifery Council. Implementation of a framework for the standard for post-registration nursing. London, Nursing & Midwifery Council, 2005.
- Begley C, Elliott N, Lior J, et al. Differences between clinical specialist and advanced practitioner clinical practice, leadership, and research roles, responsibilities, and perceived outcomes (SCAPE study). *J Adv Nurs* 2013; 69: 1323–1337.
- Royal College of Nursing. What are the essential attributes of specialist and advanced nursing practice? A rapid review of key UK literature. London, The Evidence Centre RCN, 2015.
- NHS Employers. About Agenda for Change. www.nhsemployers.org/your-workforce/pay-and-reward/pay/agenda-for-change-pay/how-agenda-for-change-works Date last updated: March 27, 2017. Date last accessed: June 20, 2017.
- NHS Employers. National job profiles. www.nhsemployers.org/your-workforce/pay-and-reward/pay/job-evaluation/national-job-profiles Date last updated: April 26, 2017. Date last accessed: June 6, 2017.
- Transforming Practice. In: The Future of Nursing: Leading Change, Advancing Health. Institute of Medicine (US) Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing, at the Institute of Medicine. Washington (DC), National Academies Press, 2011.
- Royal College of Nursing. Advanced nurse practitioners: an RCN guide to the advanced nurse practitioner role, competences and programme accreditation. www.wales.nhs.uk/sitesplus/documents/861/RCN%20Competences%20Advanced%20Nurse%20Practitioners.pdf Date last updated: 2010; date last accessed: January 05, 2018.
- International Council of Nurses (ICN) Scope of Nursing Practice 2013. www.icn.ch/publications/position-statements/ Date last accessed: June 20, 2017.
- Williamson S, Twelvetree T, Thompson J, et al. An ethnographic study exploring the role of ward-based Advanced Nurse Practitioners in an acute medical setting. *J Adv Nurs* 2012; 68: 1579–1588.
- Melby V, Gillespie M, Martin S. Emergency nurse practitioners: the views of patients and hospital staff at a major acute trust in the UK. *J Clin Nurs* 2011; 20: 236–246.
- Royal College of Nursing. Credentialing for Advanced Level Nursing Practice Handbook. London, Royal College of Nursing, 2018.
- Oulton J. The global nursing shortage: an overview of issues and actions. *Policy Polit Nurs Pract* 2006; 7: Suppl. 3, 345–395.
- Byrne G, Topping A, Kendall S, et al. Developing a national mentorship scheme to enhance the contribution of clinical academics to health care. *Nurse Res* 2014; 22: 23–28.