

ORIGINAL ARTICLE

Clinical haemophilia

# The UK haemophilia specialist nurse: Competencies fit for practice in the 21st century

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## Abstract

**Introduction:** Nurses play a central co-ordinating role in delivering comprehensive care for people with haemophilia and allied bleeding disorders, for which they need a broad range of competencies. The UK Haemophilia Nurses Association (HNA) published a role description in 1994 which was developed into a competency framework in 2014. This has now been updated to reflect current educational and clinical practice.

**Aim:** To summarize the evidence supporting the nurse's advanced role within haemophilia care and develop new competencies to deliver comprehensive care within a multidisciplinary team.

**Methods:** Systematic reviews were identified by PubMed literature search. The HNA conducted workshops to consult its membership, and the authors incorporated this input to update its competency framework within the structure outlined by Health Education England in multiprofessional framework for advanced clinical practice in England (2017).

**Results:** The proposed framework includes five domains (Clinical knowledge, Clinical/direct care, Communication and support, Collaborative practice and Research) supported by indicators for four levels of practice (beginner, competent, proficient and expert). The framework is a tool which nurses and their managers can use to assess skills and knowledge, and identify learning needs appropriate to personal development and improve patient care and outcomes.

**Conclusion:** The HNA has developed a new competency framework to provide a strong foundation for haemophilia specialist nurses to continue improving services for people living with bleeding disorders and their families, as well as supporting personal development alongside new therapeutic options, models of care and follow-up.

## KEYWORDS

clinical competence, comprehensive health care, cost-effectiveness, haemophilia, nurse's role, quality indicators

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## 1 | INTRODUCTION

Guidance on the management of haemophilia recommends the delivery of comprehensive care by a multidisciplinary team (MDT).<sup>1</sup> This defines the nurse's role as co-ordinating the provision of care, educating patients and their families, and acting as the first point of contact for patients and their families. Nurses are responsible for initial clinical assessment, and for ensuring appropriate treatment is administered promptly in acute situations and for managing continuing care and follow-up.

The UK Haemophilia Nurses Association (HNA) believes that nurse training should ensure competency in key areas if haemophilia nurses are to be effective practitioners within the MDT. In 1994, it published a 'role description for clinical nurse specialists in haemophilia and related disorders'.<sup>2</sup> Recognising nurses as part of the MDT, the description listed the major roles carried out by haemophilia nurse specialists (clinical practice, advocacy, advice, education, research) and described examples of specific activities for each. The role of 'navigator/co-ordinator' was not specifically mentioned but activities falling within that term were listed under the core headings and included referral, ensuring continuity of care, liaising with external personnel and agencies, and advising other health professionals and management.

Since publishing the role description, the HNA has actively supported nurses to develop their role. The HNA used this experience to develop its competency framework in 2014<sup>3</sup> which was further evaluated by the nurses committee of the European Association of Haemophilia and Allied Disorders who published a European curriculum for nurses working in haemophilia care in 2016.<sup>4</sup> The HNA has since updated its competency framework in light of changes to UK nurse education (where all nurses are educated to at least bachelor's degree level) and to reflect the changing scope of nursing within the UK into advanced practice roles underpinned by a published evidence base and founded on established educational principles. This review summarizes the evidence examining the nurse's advanced role across all specialties within UK nursing practice, with a specific focus on bleeding disorder care. It reviews the effectiveness of advanced nursing practice, including financial implications and describes the development of competencies that will enable nurses to be effective advanced practitioners within the MDTs delivering comprehensive care.

## 2 | COST-EFFECTIVENESS OF ADVANCED NURSING PRACTICE

There have been several systematic reviews of studies of the cost-effectiveness of advanced nursing practice (ie, nurse practitioners and clinical nurse specialists). Some have included different specialties<sup>5-9</sup> but two complementary reviews have focused on long-term conditions as a surrogate for rare diseases and haemophilia care.<sup>10,11</sup> These reviews included studies published during overlapping time periods, leading to duplication of data.

These systematic reviews demonstrate the global interest in assessing the impact of services provided by specialist nurses across a range of specialties. The overall trend suggests that nurse-led services, where nurses can autonomously review and treat patients are associated with outcomes at least as good as those associated with traditional medical models in other acute hospital settings.<sup>12</sup> There is some evidence that they are cost-effective compared with traditional or physician-led models: they are at least as effective and less or equally expensive, though resource consumption is variable.<sup>13</sup> However, published studies often have methodological shortcomings and the extent to which these differences reflect circumstances peculiar to one service rather than inherent differences between the service models is not clear.

## 3 | COST-EFFECTIVENESS OF COMPREHENSIVE CARE

Two related systematic reviews have evaluated the impact of comprehensive care (termed integrated care in these publications) on the management of long-term conditions (LTCs: asthma, chronic obstructive lung disease, diabetes, heart failure)<sup>9</sup> and haemophilia.<sup>10</sup> Nurses were part of the MDT in almost all studies but their roles were not described.

The review of LTCs (an overview of systematic reviews) was carried out to draw lessons for the formulation of strategies to manage rare diseases and to inform the development of a management guideline on haemophilia<sup>14</sup> and was an update of an earlier review of studies published up to 2012.<sup>15</sup> This had concluded that comprehensive care generally had beneficial effects by reducing hospital admissions and readmissions, improving adherence to treatment guidelines and improving quality of life. There was little evidence that costs were reduced and several studies had methodological failings. The update included studies published between 2012 up to the beginning of 2016. It concluded that comprehensive care was associated with an improvement in function and lower mortality, shorter hospital stays and probably fewer emergency visits. There was no evidence of improvement in quality of life or a reduction in missed days at school or work. The authors concluded that the findings were generally applicable to the management of haemophilia, though data from the heart failure population could not be extrapolated due to differences in age and some outcomes were not applicable to the haemophilia population.

A complementary systematic review of comprehensive care models in the management of haemophilia identified eight comparative and 19 non-comparative studies published up to 2015.<sup>10</sup> The report focused on an analysis of the comparative studies. A meta-analysis could not be carried out due to differences in study designs and outcomes. Although the risk of bias was low, the quality of evidence was rated low or very low. Overall, the analysis suggested that comprehensive care reduced mortality, emergency room and walk-in clinic visits, hospital admissions and length of stay, and days missed from school or work.

#### 4 | COST-EFFECTIVENESS OF HAEMOPHILIA SPECIALIST NURSES

A survey of haemophilia nurse specialists in the UK National Health Service (NHS) estimated that the work of each nurse was associated with an estimated minimum saving of £83 000 (US \$108 000; €99 000) in emergency visits avoided and £50 000–£100 000 (US\$65 000–130 000; €60 000–120 000) annually in clinic appointments in which nurses had replaced consultant physicians.<sup>16</sup> The study found that nurses' roles were complex and multifaceted and included activities that are recognized as core to the role (eg, management, education and co-ordination of care) but for which financial cost could not be estimated because they could not be coded for analysis in the NHS coding system. Further, some haemophilia nurses provided care for people with a wide range of disorders other than inherited bleeding disorders, substantially adding to their workload. The findings are limited by the low response rate, (10 from a total of 50 nurses contacted), although the respondents were evenly distributed across the UK and represented nurses at three levels of expertise. Non-responses were probably due to the time required to complete the weekly job plan using the Apollo nursing resource software, an online nursing resource for specialist nurses to communicate about their work and its benefit for patients ([www.apollonursingresource.com](http://www.apollonursingresource.com)).

Although nurse-led clinics for patients with bleeding disorders are becoming increasingly common,<sup>17</sup> apart from cost-effectiveness there is limited evidence that they are acceptable to patients.<sup>18,19</sup> This is an area that requires further assessment.

#### 5 | DEVELOPING COMPETENCIES FOR HAEMOPHILIA NURSE SPECIALISTS

Specialist nurses, in the UK are registered nurses who practice at an advanced level to manage and improve patient care, satisfaction and outcomes, have a similar and broad spectrum of roles regardless of the specialty in which they work<sup>20-25</sup> due to the commonality of traditional nursing functions and their more recently developed roles as patient advocates and service co-ordinators/navigation. The HNA was in the vanguard of professional development when it published the role description for haemophilia nurse specialists in 1994,<sup>2</sup> providing the model from which the UK haemophilia nursing profession has since developed.

Subsequently, the concept of competencies was introduced to provide a standard to support individuals to maintain fitness for practice and encourage professional and personal development.<sup>26-28</sup> In 2014, a working party of experienced nurses agreed a consensus statement on a core competency framework that would enable haemophilia nurse specialists to carry out their roles effectively.<sup>3</sup>

This was intended to establish:

*a baseline educational and practical skills forum for nurses new to haemophilia, which allows progression*

*through personalized development and assessment, to competence at all levels of haemophilia nursing. Many aspects of the framework include transferrable skills such as communication skills, so even 'novice' haemophilia nurses are part way along the road to haemophilia competence.*

The HNA consensus statement replaced the Royal College of Nursing (RCN)'s five functions for all nurses (clinical practice, advocacy, advice, education and research) with five new core domains (communication, research, education, support and treatment) and an additional six satellite domains (women, children, leadership, inhibitors, genetics and physiotherapy). Examples were provided of activities in each domain at four levels of expertise ranging from novice/advanced beginner to expert/specialist nurse. It was envisaged the competencies could be used to identify areas for further education and learning as part of formal (manager appraisal, objective setting, etc) and informal (own assessment) development and, while it was developed primarily from UK models of nurse training, it would offer a basis for continued professional development and appraisal elsewhere.

In 2017, Health Education England published a *multiprofessional framework for advanced clinical practice in England*, providing guidance on developing a common framework of competencies for all health professionals practising at an advanced level in the NHS.<sup>29</sup> This development made it clear that the designation 'advanced practitioner' ('an experienced registered healthcare practitioner, with a high degree of autonomy and complex decision-making underpinned by a masters level degree encompassing clinical practice, leadership and management, education and research and area specific clinical competence') would now be supported by well-defined standards of expertise across all specialties:

*As a result, for the first time, a national definition and framework of what Advanced Clinical Practice is and what the requirements for entry are. This will ensure that there is national consistency across the role and to ensure that advanced clinical practitioners, colleagues, employers and patients clearly understand the role.*

This framework provides current and future advanced care practitioners with guidance and principles that they should follow throughout their professional lives and clearly outlines a career pathway into and through the profession. It describes four pillars of practice—clinical practice, leadership and management, education and research—each containing a set of capabilities (effectively, areas of knowledge) which all advanced clinical practitioners should attain. The guidance also describes how the NHS should train and deploy advanced practitioners. The capabilities apply to professionals at an advanced level of practice regardless of their discipline or specialty. It is therefore useful to clarify the implications of capabilities by mapping them to the roles carried out by specialist haemophilia nurses.

The original HNA competency framework incorporated the concepts of the RCN's four pillars of practice competency domains

(clinical/direct care, leadership and collaborative practice, improving quality and developing practice, developing self and others), republished in 2018.<sup>30</sup>

In 2018, the HNA consulted its membership in order to update this competency framework, and this was done through three regional workshops attended by 66 haemophilia nurses who discussed areas and levels of competence. The time frame for moving from beginner to expert was developed at the HNA annual meeting in 2018 where delegates were asked to rank their own level of competence alongside time in haemophilia practice resulting in a consensus based on average time in practice. The content of the competency was developed through agreement of nurses at each of the regional workshops as well as a final review by all members of the HNA at their annual meeting.

Overall, the HNA competencies are designed to ensure that the UK has a body of haemophilia nurse specialists:

- with an expert *clinical knowledge* of haemophilia and other bleeding disorders (domain 1)
- who are skilled in *clinical/direct care* (domain 2)
- offering *communication and support* to patients and families affected by bleeding disorders (domain 3)

- who benefit from *collaborative practice* within the haemophilia MDT and wider specialities (domain 4), and
- who engage in *research* in order to achieve better care standards and practice for patients, carers and families (domain 5).

New competency domains have been selected because of the following:

- *Clinical knowledge*—developing clinical knowledge is a continuous process and at all levels nurses need to understand and continue to develop the skills to access research and use information systems, and develop and apply critical appraisal and evaluation skills to ensure practice is based on the best available evidence. Indicators of the additional underpinning knowledge needed to be a competent nurse in haemophilia care/practice are shown in Table 1.
- *Clinical/direct care*—excellent nursing practice has been described as a dynamic process that integrates the best theoretical and practice knowledge when working with patients.<sup>31</sup> For haemophilia nurses, this includes providing effective interventions that address the specific needs of individuals with bleeding disorders and enables them to improve the health and wellbeing of

**TABLE 1** Indicators of the clinical knowledge needed to be a competent nurse in haemophilia practice (domain 1)

Level	Indicators
1	<p><b>Understands</b> the variety of different bleeding disorders and their hereditary nature</p> <p><b>Recognizes</b> the signs and symptoms of the main bleeding disorders</p> <p><b>Recognizes</b> the risk factors to health for individuals and families affected by bleeding disorders</p> <p><b>Understands</b> the different treatment strategies (eg, prophylaxis vs on-demand) and treatment types (eg, replacement/bypassing/rebalancing of haemostasis) applicable to the main bleeding disorders</p>
2	<p><b>Recognizes</b> the complications of bleeds that may arise from the condition and its treatment</p> <p><b>Recognizes</b> risk factors for inhibitor development and has detailed knowledge of typical presenting symptoms and laboratory results associated with inhibitors</p> <p><b>Understands</b> the rationale for different product choices and treatment regimes</p> <p><b>Demonstrates knowledge</b> of treatment pathways for different patient groups</p> <p><b>Knows</b> which laboratory tests are available for monitoring therapy and is able to interpret test results</p>
3	<p><b>Demonstrates</b> detailed knowledge of presenting symptoms of different bleeding disorders and is able to relate these to the underlying pathophysiology</p> <p><b>Understands</b> inhibitor screening/detection protocols</p> <p><b>Recognizes</b> the risk factors for individuals with bleeding disorders and can identify situations in which referral is required</p> <p><b>Demonstrates awareness</b> of the comorbidities that may complicate treatment of people with bleeding disorders</p> <p><b>Shares</b> clinical knowledge with colleagues</p> <p><b>Demonstrates</b> understanding of the principles of pharmacokinetics in relation to treatment administration</p>
4	<p><b>Demonstrates</b> detailed knowledge of the physical, psychological and emotional needs of patients with bleeding disorders and their families</p> <p><b>Contributes</b> to the development of clinical knowledge through research and education</p> <p><b>Demonstrates</b> detailed knowledge and understanding of mechanisms of action of newly available treatments and those in clinical trials</p>

individuals. The indicators shown in Table 2 show the range of actions for delivery of effective clinical/direct care by haemophilia nurses.

- *Communication and support*—effective communication with patients, carers, families and colleagues is at the centre of providing quality nursing care and is primarily achieved as a result of building good working partnerships and therapeutic relationships.<sup>32</sup> Providing support underpins the provision of evidence-based patient-centred care: focusing care on the needs of the person and family rather than the needs of the service, and considering their well-being as well as their physical health. Accurate, timely and effective exchange of information between people can enhance understanding, drive action and facilitate teamwork. The indicators in Table 3 show the range of areas for effective communication and support provided by specialist haemophilia nurses.
- *Collaborative practice*—effective management requires the provision of a comprehensive care programme delivered by a

multidisciplinary team of healthcare professionals.<sup>33</sup> Collaborative practice is defined by the World Health Organization as a situation that occurs 'when multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care'.<sup>34</sup> The indicators shown in Table 4 are essential to the provision of effective services, education and research by specialist haemophilia nurses.

- *Research*—in order for nurses to practice evidence-based medicine, evidence is needed and is often generated through large clinical trials of investigational medical products. With increasing haemophilia care in the UK being nurse-led, nurses should be at the forefront of introducing new treatments to patients. But more research beyond clinical trials is needed. Furthermore, with their knowledge of bleeding disorders and their everyday hands-on experience of direct patient care, nurses are perfectly placed to identify gaps in practice, construct research questions, design

Level	Indicators
1	<p><b>Participates</b>, under supervision, in teaching and training of patients and families for home therapy. This includes factor storage, use, transportation and disposal</p> <p><b>Administers</b> clotting factor under supervision</p> <p><b>Takes</b> a simple family history of common bleeding disorders and draws a family tree</p> <p><b>Participates</b>, under supervision, in clinical decision-making</p>
2	<p><b>Implements</b>, manages and evaluates individual home treatment training</p> <p><b>Administers</b> prescribed coagulation factors and other pharmaceutical treatments</p> <p><b>Takes</b> a family history and draws a family tree for those with complex bleeding disorders</p> <p><b>Understands</b> how genetic testing aids diagnosis and assessment of risk of inheritance for family members</p> <p><b>Makes clinical decisions</b> and develops treatment plans in non-complicated situations</p> <p><b>Assesses pain</b> and proposes basic management strategies</p>
3	<p><b>Develops</b> home therapy training programmes and facilitates best practice for patients</p> <p><b>Takes</b> a multigenerational family history for those with bleeding disorders and is able to assess the risk to other family members and arrange referral and diagnosis for those at risk</p> <p><b>Counsels</b> carriers of haemophilia about options for planning a family</p> <p><b>Begins</b> to practice autonomously and supervise the practice of others</p> <p><b>Determines</b> differential diagnoses, using examination and investigation skills</p> <p><b>Provides</b> personalised care based on individual risks, needs and preferences of patients</p> <p><b>Manages</b> complex cases under supervision</p> <p><b>Works</b> with patients and families to co-ordinate/plan access to interventions across the treatment pathway</p> <p><b>Assesses</b> physiological functioning and develops appropriate intervention plans</p> <p><b>Assesses</b> psychological functioning and develops appropriate intervention plans</p> <p><b>Assesses</b> inhibitor treatment response and develops treatment plans for bleed management</p> <p><b>Prepares</b> complex treatment plans with support of medical colleague for, for example, patients undergoing surgery</p>
4	<p><b>Prescribes</b> replacement therapy and other treatments in line with qualification</p> <p><b>Practices</b> autonomously and supervises the practice of others</p> <p><b>Determines need</b> for interventions and additional support, for example additional laboratory/radiology testing or advanced pain management</p> <p><b>Refers</b> to other colleagues and services where appropriate</p> <p><b>Manages</b> complex cases</p> <p><b>Develops</b> service innovations designed to improve service-user outcomes</p> <p><b>Implements</b> innovative-based care in practice</p>

**TABLE 2** Indicators of effective clinical/direct care by haemophilia nurses (domain 2)

**TABLE 3** Indicators of effective communication and support provided by specialist haemophilia nurses (domain 3)

Level	Indicators
1	<p><b>Listens</b> to patients' and their families' views on health and wellbeing and responds appropriately, remaining responsive to the patients' choices and coping' mechanisms</p> <p><b>Observes</b> patient/families behaviour around their condition and records unexpected changes and concerns, escalating them to a senior team member where appropriate</p> <p><b>Assesses</b> the potential impact of bleeding disorders on patient's lifestyle, cultural beliefs and support systems</p> <p><b>Communicates with</b> awareness of the issues that underpin individual spiritual views</p>
2	<p><b>Communicates</b> effectively with patients/families in a one-to-one setting, discussing the individual's views and knowledge of their condition and their attitudes towards treatment</p> <p><b>Listens to and communicates with</b> patients in an age/developmentally appropriate manner in order to develop effective therapeutic relationships that will facilitate clinical/direct care</p> <p><b>Teaches and assesses</b> in clinical/direct care situations</p> <p><b>Reviews</b> self-management skills of young people to support them through transition to adult care</p> <p><b>Recognises</b> the impact that cultural, legal and ethical concerns may have on reproductive choices</p> <p><b>Facilitates discussion</b> in relation to spiritual and cultural issues, and organises appropriate support mechanisms for spiritual/cultural care</p> <p><b>Communicates</b> awareness of range of available support services to patients, carers and families</p> <p><b>Enables</b> patients/families to monitor treatment and their responses to it</p>
3	<p><b>Enables</b> patients and families independently to manage bleeding symptoms where appropriate and provides a pathway when further health care is required</p> <p><b>Supervises</b> care provision and requirements of individuals needing multiagency services</p> <p><b>Manages</b> emotionally challenging situations</p> <p><b>Supports</b> patients to make informed choices regarding evidence-based treatment and clinical/direct care</p> <p><b>Explains</b> coagulation mechanisms and inheritance to patients/families so that they understand the condition and its treatment and can make informed health care decisions</p> <p><b>Communicates and supports</b> informed decision-making in the care pathways available to specific patient groups—neonates, children and young people with bleeding disorders (including transition), adult men with haemophilia, girls/women with haemophilia (symptomatic and asymptomatic), older adults with comorbidities, those with additional needs (eg, learning disabilities)</p> <p><b>Enables</b> patients to make informed choices about their care and how to communicate their needs to other healthcare professionals</p> <p><b>Communicates</b> the results of genetic tests to patients and families, taking account of the impact that such information may have on individuals and families</p> <p><b>Initiates</b> referral to counselling/ psychological health/social services</p> <p><b>Understands</b> assent/consent processes and acts as an advocate for children and young people for children, adults and vulnerable people</p> <p><b>Challenges</b> behaviour that is detrimental to the individuals' health</p> <p><b>Plans and delivers</b> teaching interventions for patients</p> <p><b>Takes</b> a leadership role in patient advocacy</p> <p><b>Uses</b> clinical supervision to reflect critically upon their developing clinical expertise and also on development of others</p>
4	<p><b>Uses</b> detailed knowledge to initiate access to support for specific patient groups—neonates, children and young people with bleeding disorders (including transition), adult men with haemophilia, girls/women with haemophilia (symptomatic and asymptomatic), older adults with comorbidities, those with additional needs (eg, learning disabilities)</p> <p><b>Recognizes</b> when ethical and legal issues arise and initiates discussion at a professional level</p> <p><b>Strategically evaluates</b> patients' educational needs and develops responsive programmes</p> <p><b>Uses and provides</b> clinical supervision and support</p>

audits and studies, collect and analyse data in order to provide the evidence that leads to improved care. A central goal of nursing research is to achieve improved care standards and practice for patients, carers and families. The indicators in Table 5 show the contribution of haemophilia nurses.

Benner, a nursing theorist, is recognized for developing a model of clinical competence which describes five levels of learning and skill acquisition (novice to expert) through which nurses progress as their career develops and their professionalism grows.<sup>22</sup> Nurses in the UK now enter the profession at degree level and may have passed the novice stage due to the inclusion of clinical competencies in their degree pathway which were not included when Benner designed her theoretical model. The framework assumes that nurses

start with a good understanding of the basics of nursing care (such as performing venepuncture, previously an extended role) and of practising evidence-based care, using available resources to maintain excellent clinical outcomes. It focuses instead on those interventions that address the specific needs of individuals with bleeding disorders enabling improvement in the health and well-being of affected individuals.

The HNA framework contains four levels of practice and an indicative timeframe within which a UK nurse may reasonably have been in haemophilia practice; this should be interpreted cautiously because the rate at which nurses will gain experience will depend on the level of clinical activity in their centre, the roles that nurses are allowed to undertake in the UK vs. other countries the nurse may have come from and the transferability of skills from previous roles:



Level	Indicators
1	<p><b>Demonstrates</b> understanding of the roles of team members</p> <p><b>Actively participates</b> as a member of a team in the decision-making process</p> <p><b>Works</b> collaboratively with other team members to provide individualised care</p> <p><b>Demonstrates</b> a working knowledge of the range of specialist services available</p>
2	<p><b>Makes</b> referrals to other members of the multidisciplinary team</p> <p><b>Formulates</b> care plans in liaison with other members of the multidisciplinary team</p> <p><b>Liaises</b> with referral agencies under supervision</p>
3	<p><b>Co-ordinates</b> more complex clinical interventions (such as complex surgery, perhaps off site from the haemophilia service)</p> <p><b>Represents</b> the multidisciplinary team in multiagency settings</p> <p><b>Facilitates</b> development of colleagues in the multidisciplinary team, empowering, motivating and supporting them to develop their clinical skills</p> <p><b>Plays</b> an active role in functioning of the multidisciplinary team, initiating and leading discussions, facilitating decision-making, and mediating and managing conflict</p> <p><b>Makes</b> referral to services outside the multidisciplinary team</p>
4	<p><b>Takes responsibility</b> for the service-wide quality of care</p> <p><b>Negotiates</b> improved service provision and resource allocation for people with bleeding disorders</p> <p><b>Develops</b> a culture of continuous education and improvement of clinical skills</p>

**TABLE 4** Indicators of collaborative practice needed for haemophilia nurses to make an active contribution as a member of the multidisciplinary team (domain 4)

Level	Indicators
1	<p><b>Recognizes</b> need for data collection in haemophilia care and management</p> <p><b>Works</b> collaboratively with multidisciplinary colleagues in the conduct of clinical trials, studies and nurse-led research</p>
2	<p><b>Critically analyses</b> the principles of care delivery and uses these to inform practice</p> <p><b>Participates</b> in audit and clinical outcomes assessment through patient satisfaction surveys, basic service reviews and audits, and presents findings to the multidisciplinary team</p> <p><b>Understands</b> the implications of audit data and uses this to effectively manage resources</p> <p><b>Understands</b> and proactively manages local systems for stock management and ordering</p> <p><b>Develops</b> awareness of current clinical trials</p>
3	<p><b>Develops</b> audit procedures and uses audit data to improve service delivery. For example, nurse-led clinic reviews, either by telephone or face-to-face</p> <p><b>Mentors</b> others in their audits. Shares knowledge via websites, presentations, conferences, and publication</p> <p><b>Participates</b> in current clinical trials and has a good awareness of upcoming clinical trials</p> <p><b>Participates</b> and leads nursing research and sharing the results through presentation at local, national, international level and publication</p>
4	<p><b>Initiates and leads</b> research projects, presenting and publishing the findings</p> <p><b>Enables</b> colleagues to participate in research through mentoring and coaching</p>

**TABLE 5** Indicators of the involvement of haemophilia nurses in research to achieve better care standards and practice for patients, carers and families (domain 5)

- beginner, in practice for 0-6 months (level 1)
- competent, in practice for over 6 months (level 2)
- proficient, in practice for 18-24 months (level 3)
- expert, in practice for a minimum of 3 years (level 4).

Each level of practice includes indicators that provide a standard against which nurses can measure their personal practice. Where possible, evidence sources supporting the indicators will be included on the electronic version of the framework (currently in development). These will include guidelines, publications and other

resources, as well as pointers to bleeding disorder-specific education and training opportunities.

The principal aim of the competency framework is as a tool for practitioners to ensure that they continue to develop and meet their own individual professional and educational requirements. It is an aid for nurses within the field of inherited bleeding disorders to use their previous experience and expertise including transferable skills. It is reasonable to expect that they may have already attained competencies in some areas that are more advanced than others.

It is intended that the framework is seen as a fluid tool, within which nurses and their managers can assess existing skills and knowledge, and identify learning needs appropriate to personal development. Not all nurses will remain permanently within the specialty, or wish to develop into advanced practitioners, but all should be on a life-long learning path to improve patient care and outcomes. Haemophilia nurses may not be managed by a senior nurse with experience in the speciality; the framework is a guide for them to share personal development needs and goals as well as achievements during progress and development reviews.

Development of an electronic version of the framework will allow assessment of the educational needs of the haemophilia nurse population informing the education and training provision required. It may also be possible to develop an interface that allows haemophilia teams to demonstrate the overall competence and development needs within the centre (available at [www.haemn.com](http://www.haemn.com)).

## 6 | SUMMARY

The specialist nurse has a central role in the haemophilia MDT, meeting the clinical needs of the patient and family/carers, co-ordinating and leading the delivery of care by other MDT members and accessing other specialties when needed. This role is supported by a large body of evidence showing that outcomes are as good or better than other models, though there are methodological shortcomings with studies that have assessed the economic impact of nurse-led services in general. To be effective in a specialist role, nurses need a range of skills that go beyond traditional boundaries. Nurses have long been at the forefront of supporting progression through continuing professional development. The HNA has developed a new competency framework that will provide a strong practice foundation for haemophilia specialist nurses to continue improving services for people living with haemophilia and their families, as well as supporting personal development alongside new therapeutic options, models of care and follow-up.

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## CONFLICT OF INTEREST

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

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