

# Futureproofing Community Children's Nursing

RCN guidance

CLINICAL PROFESSIONAL RESOURCE





# Acknowledgements

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## Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

## Description

This guidance has been developed as a resource and framework for community children's nursing services.

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# 1. Introduction

This Royal College of Nursing (RCN) publication is for health care professionals, service providers and those involved with planning and commissioning services. It sets out the RCN's perspective on contemporary and future children and young people's (CYP) nursing services in the home and community setting. It also underlines the increasingly crucial role played by community children's nurses (CCN) as they provide integrated care closer to home.

The guidance explores the legislative and policy agenda, defines the role of the CCN, sets out the core principles of providing care, considers variations in how the needs of families are assessed across the four countries of the United Kingdom (UK) and outlines examples of current models of care and service delivery. It also covers:

- informatics and eHealth
- the school nurse role
- outcome measurement for families
- development of services (whilst ensuring sustainability of these services)
- planning for the future – how to meet the educational needs of professionals and develop future leaders in this field of practice.

Historically, community children's nursing has never had the support of an agreed UK-wide framework or universal offer as outlined within for example public health nursing (as with health visiting and school nursing). This leaves the CCN role as flexible and, seemingly, without boundaries. Within the four countries, developments and changes to the role will continue and, consequently, variation in each country will remain as practices evolve. As practice developments occur separately within the four countries, the RCN, as a professional body, needs to ensure good practice is communicated as widely as possible. Such dissemination will enable practices to align and reduce the variation across the UK.

Notably, Scotland has recently developed a framework for health visiting and school nursing. The basis of a universal offer for community children's nursing, as a distinct field of practice, is offered by work undertaken jointly by the

Queens Nursing Institute, Public Health England and the Department of Health for England (2018).

In 2013, a review in Scotland of the public health nursing role, as defined within *Nursing for Health 2001* (Scottish Government, 2001), was undertaken. A Chief Executive Letter (CEL 13) stated that the role should be refocused and the titles of health visitor and school nurse reintroduced (Scottish Government, 2013).

- The role of health visitor would focus on children 0 to 5 years of age, (including preconception) and the role of the school nurse would focus on school years (children aged 5 to 19 years).
- Health visitors and school nurses would continue to be on the third part of the NMC register (Public Health Nursing).
- There was an acknowledgement at this review that the role of the community children's nurse would need to be reviewed, along with the roles of the wider health team involved with children at school.

Subsequent changes, for example in the role of the school health nurse, echo the variation of service provision across the UK (Scotland reintroduces health visitor and school nurse). A refocus on the public health perspective, has led to CCN services needing to meet aspects of care which would traditionally have been provided by school nurses, for example – school health care plans and continence care.

## 2. Background: the role of the community children's nurse

Within the UK, the development of CCN teams were identified by the Department of Health (England) as significantly contributing to, whilst supporting the safe delivery of care to CYP and their families closer to home (Hinde, et al. 2016). According to Price (2018), the first CCN team was in Rotherham in 1949 (a historical timeline of the development of community children's nursing is included in Appendix 1). Since this time, CCN teams and associated services have established themselves as an important part of the interdisciplinary and multi-agency team, aiming to provide high quality, safe and effective care whilst working in close partnership with CYP and their families.

In 2011, the Department of Health in England described four categories of community care for nursing CYP (see below and in more detail later) and CCN services as 'the bedrock of the care pathways for these groups of children' (DH, 2011).

### Four categories of community care for nursing CYP

- Children with acute and short-term conditions.
- Children with long-term conditions.
- Children with disabilities and complex conditions, including those requiring continuing care and neonates.
- Children with life-limiting and life-threatening illness, including those requiring palliative and end-of-life care.

In 2014, the RCN published *The Future of Community Children's Nursing: Challenges and Opportunities*. This stated that CCN provision was vital to families to enable them to care for their child at home. This viewpoint has not changed, and services have continued to develop throughout the UK. The Queen's Nursing Institute (QNI, Public Health England and DH, 2018) has given a clear overview of the CCN role:

'Highly complex and requires skills in negotiating, coaching, teaching and

supporting the families and carers of babies, children and young people whilst collaborating with a range of other agencies and services. Working in partnership, they enable children and young people with health needs to remain safely in the community and transition to adult services in due course.'

However, throughout the UK, models of care delivery are varied and have primarily developed in response to local geographical population need, whilst attempting to meet national policy drivers. The associated funding of such services is, at best, varied and, subsequently, there isn't a 'one size fits all' nationally defined best model of care delivery. This guidance highlights exemplars of care delivery from across the UK (whilst reflecting the variation) and the continued development of services which is ever evolving.

*Facing the Future: Together for Child Health* (RCPCH, RCGP and RCN, 2015) aims to ensure there is always high quality diagnosis and care early in the unscheduled care pathway providing care closer to home where appropriate. These published standards describe specialist CCN expertise to directly support general practice services where the needs of the child and their family are known. The standards aim to build good connectivity between hospital and CCN teams, primary and secondary care, and paediatrics and general practice.

Despite a variety of documents supporting the continued need for the CCN role, there is inconsistency and a lack of clarity amongst service providers, including commissioners, of what is encompassed within the CCN role; unlike the role of the district nurse which is clearly defined and understood by the general public and professionals alike. This challenge may also be hindered by the wide variation in service delivery models of care. CCN service provision is inconsistent throughout the UK with some areas having very little access to this specialist nursing expertise (QNI, Public Health England and DH, 2018). This inequality in service provision is due to a variety of factors such as: who funds the CCN service and where is the team based (acute or community provider with differing service priorities). The resulting outcome can affect mechanisms of communication, both internal

and across organisations. The type of service provider also makes a difference to referral pathways and clinical governance arrangements for CCN teams (which enable the provision of safe and consistent care). Acute and community providers may have differing priorities, and interpretation of national policy is consequently reflected in the model of care delivered. Work being undertaken in Scotland is seeking to secure a consistent approach to delivery of services irrespective of location and provider.

The QNI and the Queen's Nursing Institute Scotland (QNIS) worked together with experts from across the UK to develop a set of voluntary standards to support community children's nurse education and practice: *The QNI/ QNIS Voluntary Standards for Community Children's Nurse Education and Practice* (QNI/ QNIS, 2018) reflect the four categories of care as described by Department of Health for England (2011). The QNI standards can lead to a broader understanding of the CCN role, plus ensure a consistency of components within the development of future training programmes – this will underpin the role of the CCN and service development going forward. Having nationally agreed roles and defined career progression within CCN services will remove geographical variants between teams and across the four countries.

## 3. Legislation and policy

For many years there has been an increasing emphasis and associated policy directives on meeting the needs of CYP and their families in the home and community setting. Within the four countries there is emphasis on a move towards integrated working across health and social care with joint or pooled budgets.

### England

In England, several successive policies have been published which include:

- *NHS at Home: Community Children's Nursing Services* (DH, 2011)
- *Five Year Forward View* (NHS England, 2014)
- *New Care Models – Vanguard*s (NHS England, 2016)
- *The NHS Long Term Plan* (NHS England, 2019).

These have led to a change of direction for health services. However, it is evident that the focus of these policies is not exclusively related to services for CYP. Importantly, the publication of *The NHS Long Term Plan* provides a clear commitment and identification of the need to develop age appropriate models of care and, significantly for CCN services, care delivered closer to home. It is also essential to develop locally agreed models of care for CYP in the community. These can help support an increasing urgent care workload and reduce the burden on acute emergency department resources, plus provide appropriate care closer to home. *The NHS Long Term Plan* also provides a commitment to the palliative care provision for CYP, having recognised that health care costs have outpaced investment and funding arrangements.

The Children and Families Act (2014) states that a child or young person has a special educational needs and disability (SEND) if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her. The accompanying Code of Practice requires commissioning groups to work together to ensure children and young people with SEND get the education, health and care services they need; this may be published as the local offer. The role and the scope of community children's

nursing teams will be included and outlined in this offer.

### Wales

The Social Services and Well-being (Wales) Act (Welsh Government, 2014) is fundamental in supporting partnership approaches to assessing and planning the care and support needs of children and their families. A person-centred approach is used to establish wellbeing outcomes for children. Local authorities and health boards are encouraged to work together and drive integration and innovative service change.

The above work is also supported by the Well-being of Future Generations (Wales) Act 2015 (Welsh Government, 2015) which has encouraged agencies to think differently and act collectively. A future vision of a 'whole system approach to health and social care' is outlined in *A Healthier Wales: Our Plan for Health and Social Care* (Welsh Government, 2018a). This publication supports models of seamless health and social care (with a shift in resources from hospital to the community) and encourages the growth of informatics and digital technologies across agencies to support safe high quality care.

The recent Additional Learning Needs and Education Tribunal (Wales) Act 2018 (ALNET ACT) aims to improve the planning and delivery of additional learning provision through a person-centred approach to identifying needs early, putting in place effective support and monitoring, and adapting interventions to ensure they deliver desired outcomes. A draft additional learning needs code for Wales (Welsh Government, 2018b) has recently completed the consultation phase (March 2019) and a definitive document is pending.

Professionals have a responsibility to support children with medical needs in education. *Supporting Learners with Healthcare Needs* (Welsh Government, 2017a) advocates this and the guidance also includes advice on writing health care plans. The publication is intended to be used alongside *A School Nursing Framework for Wales – part 2: Nursing in Special Schools* (Welsh Government, 2018c). This guidance builds on the revised school nursing framework (Welsh Government, 2017b) which describes the core role of the specialist community public

health nurse, school nursing (SCPHN SN), based on national public health programmes and outlines categories of universal, enhanced and intensive service provision.

## Scotland

The review of public health nursing, health visiting, school nursing and CCN services for Scotland began in 2013. A Chief Executive Letter (CEL 13) (Scottish Government, 2013) stated that the current public health nursing (PHN) role, as defined within *Nursing for Health 2001* (Scottish Government, 2001), would be refocused and the titles of health visitor and school nurse reintroduced. The role of health visitor should focus on 0 to 5 years (including preconception) and that of school nurse on school years (5 to 19 years). Health visitors and school nurses continue to be registered on the third part of the Nursing and Midwifery Council Register.

The health visiting, family nurse partnership and school nursing practice models and education programmes are complete. Work continues on CCN services, the wider health team for children in school and the nursing service for children and young people who experience the care system (formally known as looked after children).

The CCN National Review (in progress at time of this publication) aims to recommend a consistent approach to care delivery.

### CCN National Review

- Explore and clarify the CCN role in Scotland.
- Clarify the interface between health visitors, family nurses, school nurses, care experienced children's teams and CCN teams.
- Scope the educational preparation required for CCNs.
- NHS Education Scotland, under the Transforming Roles Programme, to take forward discussion regarding CCN education provision in Scotland.
- Agreement on the educational preparation required for the CCN role.

- Clarification of career framework and links with children teams/roles.

*The Facing the Future: Together for Child Health* (RCPCH, RCGP and RCN, 2015) recommendations from the royal colleges, highlight the importance of the role of the CCN in service delivery which supports that of primary care services. An implementation plan has been developed and is being monitored in Scotland.

The nursing teams involved with the care and treatment in Scotland work in a multiagency model and abide by the Children and Young People (Scotland) Act 2014. The implementation of the National Practice Model for the care of all children in Scotland, *Getting it Right for Every Child* (GIRFEC), supports a multiagency joined-up approach to meeting children and young people's health and wellbeing needs.

## Northern Ireland

*Transforming Your Care. A review of Health and Social Care in Northern Ireland* (Department of Health Northern Ireland, 2011) and *Health and Wellbeing 2026: Delivering Together* (Department of Health Northern Ireland, 2016a) are the overarching programmes of work aimed at further developing Northern Ireland's health and social care system, in order to meet the current needs of individuals and families, both now, and well into the future. Emphasis is on the provision of high quality care, increasing the provision of care in the home setting, preventing ill health, co-production and improving access to care.

Regional reviews of children's services have been conducted in Northern Ireland since 2013, culminating in the publication of *A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community 2016 – 2026* (Department of Health Northern Ireland, 2016b). This strategy emphasises the need to strengthen the links between community and hospital services, alongside services within, and between, hospitals. As paediatric services develop, there will be more emphasis on community teams, with input from a range of staff: children's nurses, allied health professionals, social care professionals and support workers.

Key drivers identified in this strategy include:

- an increase in birth rate
- an increase in children surviving with complex, long-term conditions requiring intensive support
- lifestyle factors that impact on the health and wellbeing of children
- the need for more sophisticated interventions
- changing models of care so that common conditions can be managed as day cases, without a need for inpatient admissions (Department of Health Northern Ireland, 2016b).

The skills and competences of children's nurses and advanced nurse practitioners (as part of the multidisciplinary team) are recognised as key to delivering high quality services. A regional assessment tool and *Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs* (Department of Health Northern Ireland, 2009) are utilised by CCNs in partnership with families.

## 4. Models of community children's nursing services

According to *The Future of Child Health Services: New Models of Care* (Kossarova, Devakumar and Edwards 2016) new models of care have emerged to help promote the provision of joined up acute and primary care provision and to increase satisfaction with services. Moving forward, the use of eHealth strategies and telemedicine are coming to the fore, not only to assist record keeping and communication between professionals, families and agencies but also to influence how we communicate with CYP. The RCPCH's *State of Child Health: Report 2017*, suggested the use of email, websites and apps to enhance communication between individuals and professionals. Innovative practices such as these are coming to the fore and will impact on service delivery.

Whilst there are four distinct care pathways described by the Department of Health for England in 2011, the numbers of children in each category, and the location of services in many areas, do not naturally facilitate these services being provided in separate teams. However, in some areas these groups are commissioned separately despite there being obvious overlaps – for example, the child with complex needs may be receiving palliative care, alongside experiencing a short-term need for acute health provision. It may be helpful for health planners and commissioners to scope their local CCN service provision and ensure this is clearly outlined within a core offer.

Through the production of a localised core offer, and overarching joint service level specification for CCN services, service users could see a reduction in fragmentation and an increase in the integration of services delivered. CCN teams can still work with a specialist focus, but the significant factor is the associated creation of clearly defined clinical/service pathways (rather than a 'one size fits all' encompassing service) due to, for example, the differing nature of care delivered by acute or continuing care service providers.

Funding arrangements for such services in England vary and have been seen to evolve following a local review of services and national drivers. Funding considerations include: central government policy for the integration of health and social care budgets (NHS England, 2016) and the existence and development of local arrangements (as with local care partnerships where service delivery agreements exist between acute health trusts and community providers).

The publication would therefore encourage that services are reviewed, and this approach taken when recommissioning existing services.

## 5. Acute and short-term conditions

Services delivered to meet the health needs of this cohort of CYP are provided by a significant variety of service models and within these there is a variation in level of provision – some services are operational Monday to Friday, 9am to 5pm, versus 365 day working, 8am to 10pm, with increased provision to meet the needs of children reaching end of life and requiring 24/7 nursing care (also see the Life-limiting, life-threatening illness, palliative and end-of-life care section).

Children with short term/acute health needs, typically require the provision of a service that can respond with a short lead time, for example, within 24 hours from the point of referral. The aim of such service provision is to facilitate early discharge from acute hospital services, prevent re-attendance or prevent admission to Children's emergency departments through the provision of acute clinical review in the community. Such services are frequently referred to as 'hospital at home' teams and provide short-term acute care delivery/assessment in the community.

Many CCN teams, whilst not providing 'hospital at home' acute assessments of children, do meet the wider needs of children requiring short-term health intervention, for example: care and replacement of nasogastric or PEG (percutaneous endoscopic gastrostomy) tubes, tissue viability assessment and dressing changes, or pin site care following orthopaedic surgery. Community services for CYP may also include provision by specialist service teams that are largely specified by diagnosis – examples of specialty services include: oncology, cystic fibrosis, diabetes and renal.

Some larger centres within the UK provide a paediatric outpatient parental antibiotic therapy (p-OPAT) service. This is designed to facilitate the discharge of patients who need to continue with intravenous (IV) antibiotic therapy. Examples of collaborative working between community teams and the multidisciplinary team (MDT) are outlined below.

### Case study 1: Community Children's Nurse (p-OPAT Team - UH Bristol)

Patient X had been admitted to hospital with an acute onset of abdominal pain and pyrexia. Patient taken to theatre after imaging to have drainage of hepatic abscess. However, due to the location, the abscess could not be removed completely. The patient subsequently needed to have a prolonged course of IV therapy of Ceftriaxone (later switched to Ertapenem due to multi-resistant organisms). Original planned course of IV for one month. The patient had almost six months of IV therapy, until total resolution of the abscess (as she had previous relapses).

During this time, she was visited by the community team once a day, for a half an hour infusion, observations, assessment, midline care and maintenance and weekly bloods. This information was shared between the MDT, including surgical teams in two specialist centres and infectious diseases to ensure the best possible care for the patient. This collaborative working allowed her to return to school and her single parent to work. She did not have any line infections and is continuing to be monitored long term.

## **Case study 2: Evelina London Children's at home and community nursing service**

The Evelina Children's at home and community nursing team operates a seven-day service (8am to 10pm). It is an integrated model of care that has been jointly commissioned by Lambeth and Southwark and managed by the acute directorate of the Evelina London Children's Hospital.

The team operates out of three hubs (two hospital and one community), supported by mobile working on a virtual ward. There is a rapid response component to the team that can take a referral and review the child at home within three hours of discharge, up to three times a day, with clinical oversight from paediatricians. A daily huddle is held where teams from all hubs meet for handover, review, allocation and to ensure the team is working to full capacity at all times across the service.

Hospital bases and sitting in the acute directorate allow for increased visibility, raised profile of the CCNT and communication with ED/acute paediatric services, as well as increasing referrals, coupled with the clinician's confidence. Further opportunities for earlier discharge of different conditions can also be identified.

The overall aim is to reduce length of stay, admissions and ED attendance. The model allows for increased responsiveness and improved flow through a single pathway and point of access for children with acute/short-term, complex needs, continuing and palliative care from hospital to home, linking into primary care/universal services within the local community.

A pilot scheme is planned for GP referrals in the spring/summer of 2019 which will be supported by staff on the advance nurse practitioner (ANP) pathway, with ongoing management and referral into the wider team.

### **Service in action**

A complex needs child was admitted to the high dependency unit with a chest infection requiring a cubicle as MRSA positive. Once stabilised, it was identified the child could be managed at home for clinical review up to three times a day and IVAB (intravenous antibiotics). We were able to facilitate this quickly by referring into the rapid response team, while regular clinical review was needed, transferring into the team based in the community hub and on existing caseload to complete IVAB. This integrated model allowed for early discharge, decreased risk of acquired hospital infection and a responsive and seamless flow to home (and increased hospital capacity for further acute admissions).

## 6. Long-term conditions

The role of the CCN is clearly defined by the identification of, and requirement for, nursing care provision to be delivered at home or in a local community place of care, including school. Due to the variety of service models, CCN services need to be adaptable, some services will be co-located with specialist services, including clinical nurse specialists (CNS) and others in reach or outreach. Care is delivered on behalf of the specialist services, with the same endpoint of providing nursing care in the community. While it is generally accepted that this has a positive effect (Hinde et al, 2016), it is not without its challenges (Castor et al, 2017). For example, children experience a wide range of conditions requiring extensive knowledge, skills and expertise on the part of parents and professionals. Also, advancements in care have contributed to changing demographics; many children and young people now survive with complex and continuing care needs and live longer than would previously have been possible.

The emotional, physical, financial and spiritual impact of having a child with a long-term or life-limiting condition on the family have been well documented (Whiting, 2012; Coad et al., 2015; Kish et al., 2018). Additionally, care for some children can extend over many years and health, social care and educational needs may fluctuate unpredictably during this time, rendering the timely assessment, planning, delivery and evaluation of care difficult. While some families demonstrate much resilience and coping skills, others need extensive support from professionals and services.

### Example model of care: The Lifetime Nursing and Psychology Service – Sirona

A joint nursing and psychology model of care catering for children and families with complex life-limiting/life-threatening conditions. Provides bespoke care for a unique group of patients. An illustration of the type of patient that would benefit from this model would be the neuromuscular patients, in particular, young men with muscular dystrophy.

Due to the degenerative nature of the condition, early intervention from a psychological perspective is essential at diagnosis and each stage of the condition's progression.

An approach that involves the whole family and coping mechanisms, with guidance on how to share information regarding the condition with the child that is affected. From a nursing perspective, care and support is generally needed more around 10 to 12 years old as the young men lose their mobility. Then, again, this support is stepped up with respiratory deterioration and ventilation needs. Cardiac and orthopaedic issues should also be considered. With this complex condition involving multiple consultants and a large multidisciplinary team, liaison and co-ordination is paramount to insure the family and young adult feel supported and well informed. The Lifetime service works across all settings, including education and social care, to provide a robust health care plan to ensure positive outcomes are achieved.

This approach, along with joint neuromuscular and respiratory clinics, provides high quality support to this group of patients.

## 7. Disability and complex health conditions

This area includes neonates and those requiring and meeting continuing care criteria. There are now examples of integrated disability teams where the role of the CCN has become more focused on a social model of care; the CCN has taken on the role of keyworker for children with complex needs and consequently lead on care planning and person-centred reviews. Integrated multidisciplinary teams ensure a whole systems approach to the provision of holistic care for CYP and their families.

In some areas, special needs school nurses are responsible for leading care for children in special needs schools, assessing needs in school and working with school staff to ensure these needs are met. These school nurses often work alongside CCNs or make up part of the wider CCN team. This whole systems approach was explored by the British Association for Community Child Health and the British Association for Child and Adolescent Public Health, which jointly published *Introducing the Family Friendly Framework* (BACCH and BACAPH, 2014). This document was written in response to the free market approach to provision of children's services and a fear that fragmentation of services could impact on children's health outcomes.

CCNs, along with other health professionals, sit within the 'system' and form part of the child's health journey through levels of need using a graduated response model of addressing need. This means that care is provided by the right person at the right time and allows professionals to detect and react to changes as required. The skills required for a CCN working within complex systems are highlighted in *The QNI/QNIS Voluntary Standards for Community Children's Nurse Education and Practice* (QNI/QNIS, 2018), with a co-production approach to care planning alongside the management of clinical care and risk assessment.

Children with continuing care needs are required to meet national eligibility criteria, this means they can receive the bespoke care required to meet their assessed needs. An informal scoping exercise carried out by the RCN CYP Continuing and Community Care Forum in 2018, identified that there are a wide range of models and thresholds throughout England and Wales. Despite the various models of care (which may include a clearly identifiable specific continuing care team or care provided within the community children's nursing team), the role of the nurse assessor is often attributed to the CCN. The CCN may also be responsible for the case management and regular review of the package of care in addition to delivering the elements of care that are required.

When the CCN has an all-encompassing role, it can be difficult to remain impartial and without bias when completing the assessment. Also, the CCN's professional relationship with the child and family can face difficulty should the family disagree with the assessment outcome. An independent continuing care assessment nurse, employed by a clinical commissioning group or health board, would remove any conflict of interest that may arise from being both assessor and provider of care and eliminate the risk of jeopardising the care provider relationship. When managing continuing care, the competences required by the CCN include the ability to negotiate complex systems and demonstrate high level communication skills.

## Example model of continuing care

### Background

Mark is 10 years old and has complex health care issues which he has had throughout his life. Over the last year he suffered from some severe respiratory issues which resulted in him being admitted to hospital and being ventilated approximately 20 hours a day via a tracheostomy.

### Discharge planning

When Mark began to stabilise from the acute respiratory issues, the High Dependency Unit contacted the discharge coordinator in the hospital to begin planning for him to come home. As Mark's health needs had changed since he was last at home, a referral was made to continuing care for an assessment to take place. The continuing care nurse assessor working for the Clinical Commissioning Group (CCG) carried out an assessment of needs according to the *National Framework for Children and Young People's Continuing Care* (DH, 2016)\* and came to the conclusion that Mark's health needs entitled him to a health support worker for five nights of care. This information was given to the family and to the discharge coordinator. Following the assessment, a joint hospital/community discharge planning meeting was arranged. The nurse assessor and discharge co-ordinator discussed who should attend and this involved the following groups/professionals from the community:

- a continuing care nurse assessor
- a community nursing team member
- the special needs education service
- social services
- community therapists.

During the meeting it was agreed that input would be required from all the community services in order to support Mark and his family when they were at home.

Mark was already a pupil at a local special needs school but it was recognised that further support would be needed. The community nursing team carried out some training with the education staff to ensure that all were competent to support Mark's increased health needs. The education staff also provided an increase in 1:2:1 care for time spent at school. Therapy services were in place at Mark's school but plans were made to increase these.

In addition, the occupational therapist undertook a home assessment to ensure that all equipment currently in place was suitable for Mark. The community nursing team arranged the order for the new equipment required for Mark's tracheostomy and ventilator, taking advice from the hospital with regards to the type and amount required. The continuing care nurse identified a care provider to carry out the five nights of continuing care support once Mark was at home. The care providers were able to receive some training from the hospital and start to build a relationship with the family and Mark whilst he was still in hospital. The hospital also carried out training for both parents in the care of the tracheostomy and the ventilator.

Social services carried out an assessment and set up a respite service for the family at a local hospice as well as arranged provision of short breaks within the home via the direct payment scheme, allowing the family choice of how this was provided. All the changes in care were added to Mark's education, health and care plan by the special educational needs service. Throughout the planning process, the community team ensured the discharge planning co-ordinator was kept informed of progress.

### **Home**

On the day of discharge, the community nursing team visited the family at home and were there to support with the initial settling in period. In the evening, the continuing care provider (commissioned by the CCG) arrived to give care overnight and allow the parents to rest. Mark remained at home with his family for approximately three weeks, with support from the community nursing team and the care provider, before returning to school (with a phased return until he was attending full-time).

### **Ongoing support**

The community nursing team provide ongoing clinical case management in conjunction with the special needs school nurse and see Mark and the family on a regular basis. The continuing care nurse assessor provides care package management, carrying out continuing care assessments on an annual basis or if clinical needs change. The care provider attends the home five nights a week to support the family, as commissioned by the CCG.

Mark attends school five days a week during term time and is supported by the special educational needs service and has therapy input. Mark's parents arrange extra care during the school holidays, either via direct payments or they use the local hospice.

All feed into the education, health and care plan which is managed by the Special Educational Needs service.

### **Conclusion**

This example highlights the number of people involved in the discharge home from hospital for a child with complex health needs who requires continuing care. The community nursing team and the continuing care nurse are key players in the process and ongoing effective communication and rapport are central to continued care.

\* This guidance is for clinical commissioning groups in England when assessing the needs of children and young people (0 to 17 years) whose complex needs cannot be met by universal or specialist health services.

## 8. Life-limiting, life-threatening illness, palliative and end-of-life care

More than 49,000 children and young people, including babies, are estimated to have life-limiting conditions in the UK (Fraser et al, 2012), representing a wide range of over 350 diagnoses. CCN services are a key part of the core children's palliative care services and are often described as the bedrock for good palliative care.

*End of Life Care: Strengthening Choice: An inquiry Report by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care* (APPG, 2018) recognises that there are too few professionals with the skills, knowledge and experience needed to provide children's palliative care in hospitals, children's hospices and in the community.

*RCN Competencies: Palliative Care for Children and Young People* (RCN, 2018a) is a framework which sets out the specific competences required for nursing and support staff who work closely with families and other care providers to ensure the best possible quality of life for the child/young person and support for their family.

The National Institute for Health and Care Excellence's *End of Life Care for Infants, Children and Young People with Life-Limiting Conditions: Planning and Management Guideline* (NICE, 2016) recommends services should provide (when needed) children's nursing care at any time (day and night) for CYP with life-limiting conditions who are approaching end of life and are being cared for at home.

There are numerous different models of CCN provision for CYP with life-limiting conditions across the UK, providing flexible care throughout the child's care journey, from diagnosis, through ongoing supportive care, into end-of-life care and support to the family during bereavement.

These models include integrated community nursing teams, with all team members providing support to the child and family with palliative care skills and expertise available within the team; generic CCN teams supported by specialist outreach teams from the NHS, independent and voluntary sectors and hospice at home services providing community support to children and families, often working in partnership with CCN and continuing care teams. CCNs can also provide a valuable in-reach support to hospital and hospice services, and support to school nursing colleagues also involved in the palliative and end-of-life care of children and young people. It is imperative that flexibility is built into service planning and commissioning models to enable 24/7 care at end of life in community settings, which can be infrequent but are often in times of high demand.

## 9. Education and training

Along with new models of service provision, novel approaches to educating the nursing workforce fit for the future are emerging. In England, the nursing associate role is emerging and will increase the opportunities available and the Nursing and Midwifery Council (NMC) has produced new education standards (NMC, 2018a) for implementation by 2020. This includes an increased emphasis on caring for individuals and families at home and closer to home. The NMC specifies (2018b) that all future nurses will need to work in a climate of continual change with shifting demographics, adopt different models of care delivery and embrace innovative practices and rapidly-evolving technologies. Additionally, the increasing integration of health and social care services will require registered nurses to play a more proactive role in interdisciplinary teams. These requirements have implications for future CCN teams.

The skills, knowledge and competences required for nurses working with CYP in the community requires future-proofing, nursing graduates to be flexible and able to access a varied career pathway. Simulation-based education is vital to future-proofing the whole CCN service; development of such simulation programmes is an integral part of education for future nurses/ community staff and parents. The establishment of these programmes will, no doubt, require an investment of time and finances (the full potential of mechanisms of simulation are yet to be seen). It is recognised by the NMC as an innovative and safe way to learn but work is required to ensure simulation-based learning meets the learning outcomes of the NMC standards.

The CCN formal qualification is evidentially challenging to achieve due to the lack of national provision, alongside the financial and time investment required to enable future CCNs to access this route. The arena of care delivery and field of practice for CCNs has traditionally focused on the development associated with the Specialist CCN Framework. Due to the nature of care delivered, and the significant variety of nursing roles now providing care in the community setting, the educational approach needs to keep pace. There are now numerous opportunities available to nurses wishing to access nursing in the community and become either a CCN or specialist nurse with a community focus.

The key factor in the development of education for community-focused services is transferable skills and recognising the core skillset and knowledge base needed to deliver care to CYP with a wide range of health needs. Educational provision should include those nurses with: specialist roles and a recognised qualification in that field/specialty (for example, oncology nursing, palliative care, cystic fibrosis), advanced clinical roles (with the development of advanced nurse practitioners), and CCNs with a broad skillset and access to relevant modules to enable professional development.

## 10. School nursing

The impact of changes to the commissioning of public health in England to local authorities (Public Health England, 2018), has the potential to directly impact on community children's nursing. Whilst this move aligns children's public health alongside social care and education (preventing duplication of work), the local offer focuses on the specific public health interventions as laid out in the *Healthy Child Programme* (DH, 2009) and the *National Child Measurement Programme* (PHE, 2019) and does not include nursing support around specific conditions which may have been provided in the past or emotional and mental health. Although commissioning arrangements differ in the four UK countries, there is a similar focus on a core public health offer as described, for example, in the Welsh Government's *A School Nursing Framework for Wales* (2017b). This framework supports a universal and enhanced offer to ensure every child can access national screening, surveillance and immunisation programmes in the school setting.

In Scotland, *The School Nursing Role in Integrated Community Nursing Teams* (2018a) sets the school nurse's contribution within wider health and educational wellbeing teams in schools. This sits alongside announcements (Scottish Government, 2018b) of additional funding for school nursing to support children's and young people mental health services (CAMHS) interventions and a national review of CAMHS services.

CCNs have an increasing responsibility to contribute to health care planning for CYP in mainstream schools. This comprises a broad spectrum of conditions including: epilepsy, constipation management (continence), and allergy. The need for professional input into health care plans for children with complex needs is an accepted role for CCNs or special needs school nurses and a requirement of Special Educational Needs and Disability (SEND), and school health planning in Northern Ireland and Scotland. Health professionals are required to support the care planning for children with additional educational needs to ensure access to education is maintained. This role requires a governance framework to ensure that the CCN is confident to prescribe the nursing care required, and to support any training and delegation of nursing responsibilities. Professional guidance

and a framework to support the governance requirements regarding delegation are outlined in the RCN's (2018b) publication, *Meeting Health Needs in Educational and other Community Settings. A Guide for Nurses Caring for Children and Young People*.

In Wales, *Supporting Learners with Health Care Needs* (Welsh Government, 2017a) guidance provides a statutory framework for the delivery of health care needs, including the development of individual health plans. It also, for example, provides guidance to support practice on information sharing and medicines storage. It is within this context that this special schools nursing framework should be considered.

A review of school nursing provision for pupils within special schools was commissioned by the Chief Nursing Officer in 2015 to ascertain the level of input required to optimise the health and wellbeing of children and young people who receive their education in these schools. The rationale for the project was that the existing framework for the school nursing service for Wales does not include the provision for special schools.

The review highlighted a wide range of health-related issues and concerns relating to the lack of a standard approach in meeting the needs of the pupils who need special school education. The special schools nursing framework is currently being developed as other key policy drivers are simultaneously being rolled out. *A School Nursing Framework for Wales* (Welsh Government, 2017b) outlines the programmes that are being implemented. The drivers in this section consider the implications of these same programmes but from a special school nursing perspective.

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 creates the legislative framework to improve the planning and delivery of additional learning provision, through a person-centred approach to identifying needs early, putting in place effective support, and monitoring and adapting interventions to ensure they deliver desired outcomes. The role of the nurse in special school settings will be pivotal to supporting the implementation of the new assessment and delivery process and ensuring the requirements of the Act are supported is one of the key standards within this framework.

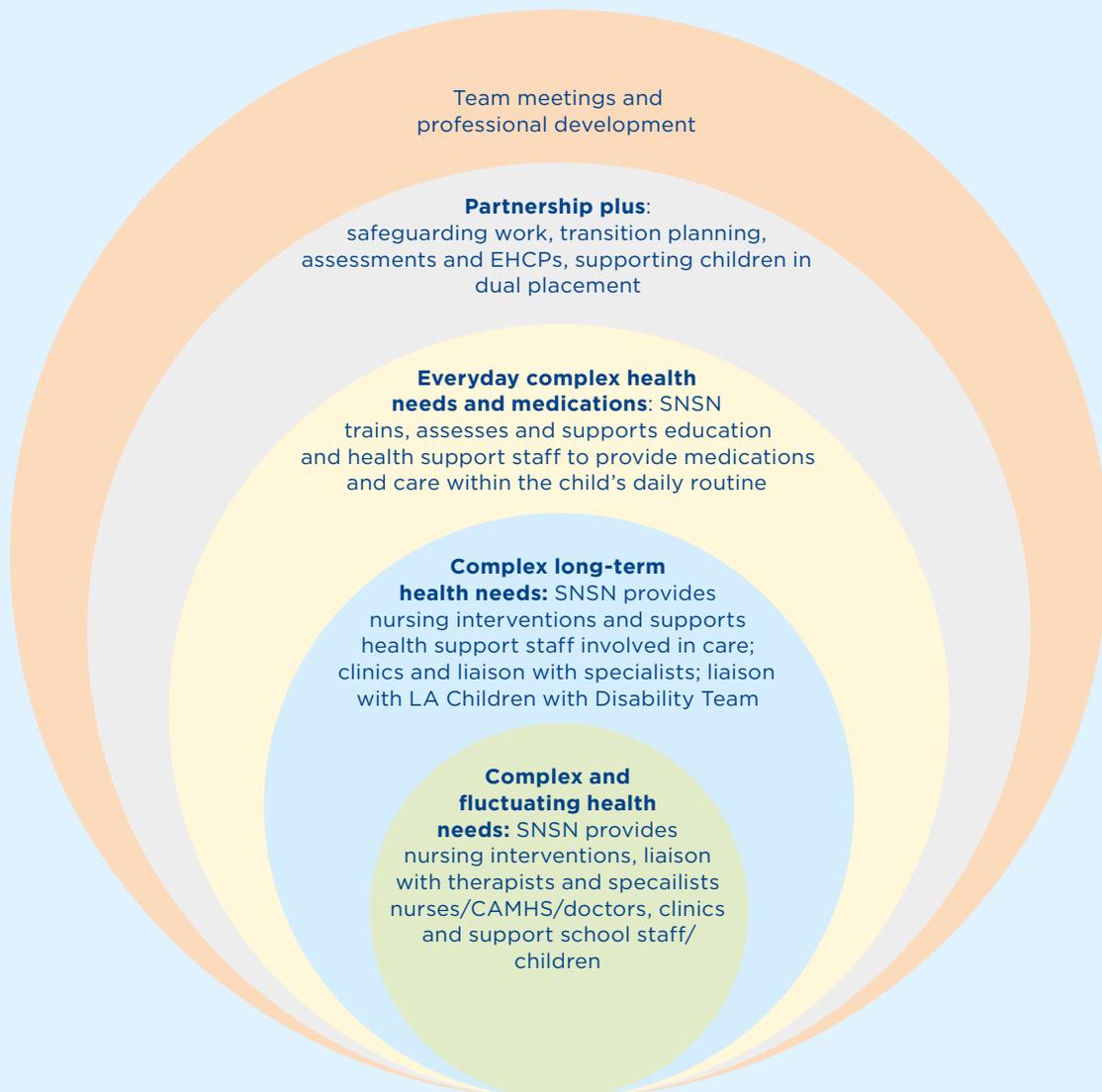
*Together for Children and Young People* was launched in Wales in 2015 by the Health and Social Services Minister. Led by the NHS, this multi-agency programme is working to reshape and refocus emotional and mental health services for children and young people in Wales, in line with the principles of prudent health

and care. Other key school-based policies that are relevant to the role of the nurse in special schools are the roll out of the Healthy Child Wales Programme and emotional literacy and support mechanisms (ELSA) (Welsh Assembly Government, 2010).

### Assessing nursing needs in school. Commissioning and workforce planning tool

A study undertaken (Williams, 2019) to identify the nursing needs of children in special schools has concluded that significant variation in nursing provision across England and South Wales exists (see Appendix 7). Using the *Assessing Nursing Needs in School; Commissioning and Workforce Planning Tool*, designed by Trudy Ward and her colleagues in West Sussex, the study reviewed schools in four local authority areas. The tool identifies five categories of care (see model below).

#### Model for special needs school nursing



Whilst a lack of guidance regarding nursing in special schools in the UK is evident, Wales has however recently produced *A School Nursing Framework for Wales – part 2: Nursing in Special Schools* (Welsh Government, 2018c)

The Commissioning and Workforce Planning study aims to influence future policy for the provision of nursing in special schools, to produce a framework for children across the UK. A series of recommendations from the report are set out (see below) which will ultimately aim to set priorities for the provision of services within special schools. The Commissioning and Workforce Planning study aims to influence future policy for the provision of nursing in special schools, to produce a framework for children across the UK.

### Recommendations

- A model for health care provision is offered to ensure that children receive care that is appropriate for their needs and provided by people with appropriate knowledge and skills
- A minimum of one SNSN should be based in every school where there are children with complex fluctuating and complex long term health needs during school hours
- The SNSN should be care coordinator for those children with nursing needs
- There is a requirement for interdepartmental Government policy that specifically addresses the needs of this vulnerable group of children.
- A national, interdepartmental commissioning framework, based on current policy, is required to provide clarity and greater equality of health needs provision in special schools.
- The commissioning framework for this group of children should ensure that health needs are commissioned alongside educational provision.
- The commissioning framework should also include public health provision and take into account the local offer for children with disability in the local area.
- The director of children's services role should provide leadership in joint commissioning to ensure that public health, specialist health, social care and education needs are met.
- A multi-agency approach to all aspects of the service, from commissioning to evaluation of services provided, is required to ensure that all needs are met.
- A joint governance framework is required to incorporate health, social care and education services, ensuring consistency of approach and shared learning.
- Joint governance arrangements should be agreed to promote consistency in provision of health services.
- There is a need for continuing care panels to consider how health needs will be met in school.

# 11. Technology

CCN teams can only continue to deliver improved services if their practice is supported by the latest technology, such as mobile working, digital platforms, telehealth and text messaging. Using remote technology (iPads and laptops) enables the CCN to instantly access clinical records to help improve patient care.

Having systems that share key patient information between health partners is essential to ensure clinicians have all relevant, available information about a patient when making decisions about their care (RCPCH, 2015). Data shared by organisations includes information on: encounters, admissions and referrals, problem history, care plans, alerts, medications, investigations, planned out-patient appointments, hospital admissions, ED attendances, child health immunisations, radiology reports and blood results. Having immediate access to key clinical information and details about all individuals involved in a person's care will help:

- prevent unnecessary admission/readmission to hospital
- prevent delayed discharges
- support faster rehabilitation
- prevent unnecessary referrals
- prevent unnecessary home visits
- enable better triage of referrals
- support faster and more effective assessment
- reduce administrative tasks, freeing up time for clinical care
- improve the patient's experience (reducing repetitive questions).

CCN teams should consider online 'one stop' resources as a source of self-help for CYP and their families – these provide opportunities to undertake health screening which, when completed, provide individually tailored advice and information. Depending on the results, the site can offer users the option to self-refer directly into their local CCN team.

The use of digitally-shared platforms helps to improve the quality of care and self-management for the CYP. A CYP, parent or carer, and any professional working with the family (health, social and education, are able to utilise the platform to access up-to-date health care plans, medication prescription information, as well as to input feedback (such as sleep diaries) and send instant messages to the CCN team. Video calling is now a part of everyday life for many people – speaking with loved ones, getting financial advice and many other activities; and tele-medicine (and the opportunities it presents) needs to keep pace with the latest technology.

## 12. Lone working and safety considerations

Due to the nature of working in the community setting, staff members involved in the process of lone working are required to risk assess. This assessment covers the procedures they will undertake and their own individual safety. The risk assessment should cover the:

- individuals they are visiting
- geographical location of the visit
- time/day of the visit
- equipment and medication being transported
- ability to park close to the residence or location of the visit
- provision of a mobile phone or device to support with lone working
- administrative support to track visits/act as a buddy.

Furthermore, professionals have a responsibility to consider the safeguarding needs of the individuals and environment where care is to be delivered.

Risk assessments should be undertaken in a systematic and structured way. The process of risk assessment needs to be undertaken prior to arranging a visit with consideration to a known risk, and significantly dynamic risk assessments need to be carried out on each visit. An example of a risk assessment framework is provided in Appendix 2. Ideally, the information contained within the risk assessment should be in an electronic format available to all professionals and accessible remotely through the use of electronic devices and electronic patient records; this will help support and enable real time live documentation.

### Information technology/ tele-health

#### Benefits for patients

- Provides greater patient choice and potentially enhances the patient's experience.
- Helps patients who have difficulty taking time off work to attend appointments, as no travel time is required and saves them time and money.
- Enables carers to attend from a different setting to support the patient, for example, even if they are at work.

#### Benefits for staff

- Virtual appointments may be a solution in settings where 'did not attend' (DNA) rates are high.
- Able to use video calls for clinical use at MDT meetings, group therapy sessions, GPs, ward rounds and local authority meetings.
- Virtual appointments helps to read a patient's body language and facial expressions, providing more information than a telephone call.
- Video calls can also be used for one-to-ones and management meetings to reduce wasted travel time and expenses claimed.

#### Benefits for carers

- Carers can attend either physical meetings between patient and clinician or virtual appointments remotely; this helps with being more closely involved in the patient's care.
- Allows carers to 'join' appointments even if they are not physically able to attend.
- Enables a carer to feel more involved.
- Enables a patient to chat with carers/family members during inpatient stay.

An integrated electronic patient record (EPR) system, the Wales Community Care Information System (WCCIS) is being introduced throughout Wales which can allow health and local authority teams to share case management through one record for every person in Wales. A nationally agreed EPR framework that meets NICE Guidance and CQC regulation, whilst providing clinical templates for assessment and measuring outcomes is recommended by the RCN to support the development of CCN services and care for CYP closer to home/in the community.

Effective record keeping is the fundamental basis of all clinical care. This method assures professionals and patients that their discussions, decisions and outcomes are recorded both for future use, for use by other clinicians, and to report on progress and determine the outcomes and effects of treatments. Organisations must be committed to the implementation of a single ERP, available to staff in all locations and at all times; for the CCN, the EPR needs to be one that has the ability to work remotely, whilst meeting best practice and regulatory requirements.

Often, the CYP with complex needs has several medication administration records, depending on the settings they attend. Electronic charts that 'follow' the CYP, support the recommendation for a single record, reduces the risk for medication errors and, where appropriate, saves time in prescribing arrangements for the CCN. Enhanced systems support medication management assurances by providing audible alerts when a medication is due and keeps a record of the amount of medication left for checking.

In 2016, an NHS Improvement Patient safety alert (NHSI, 2016) tasked all NHS funded care providers to have a system in place by 31 January 2017 for recognising and responding to the deteriorating child. Paediatric Early Warning Scores (PEWS), previously used within acute services, need to be fit for purpose in community settings and support new ways of providing care closer to home and avoid unnecessary hospital admission (See Appendix 3: Community children's nurse home assessment tool). The home assessment tool provides the basis to undertake an initial physiological/emergency assessment of a CYP's clinical status.

CCN teams should also have appropriate business contingency plans in place. These will support a manager's planning and continuity of service delivery during unplanned staff absences. The plans can be RAG rated in terms of staff at 100%, 50% and 25% staffing levels (See Appendix 5: Community Nursing RAG Contingency).

CCN teams need to clearly identify what they can provide training for and the associated costs for such training provision to external agencies. In this way, CCN teams can confidently advise other services on what training falls outside of their core offer but can be commissioned/bought in. This practice is evident within therapy services and more recently seen within school nursing provision. CCN services need to align with this or they will struggle to meet a growing demand and the competing needs. Time investment will be required to consistently provide training, but this can be a further source of income generation for CCN services.

# 13. Service planning considerations and outcome measures

CCN services should be focused on meaningful person-centred outcomes for individuals and carers, valuing impact rather than individual contacts or tasks (Evans, 2015). Commissioning CCN services should include special needs school nurses and a move from block contract commissioning, which counts numbers of contacts, to person-centred outcome based commissioning. This method can lead to streamlining the delivery of patient care (Evans, 2015).

The King's Fund (Foot et al., 2014) also suggests that community nursing needs to move away from task and contact-based care to person-centred outcome based care. Some commissioners have started to develop outcome-based commissioning for community services, focussing even more on activity.

As part of the commissioner provider contract, Foot et al., (2014) suggest that providers need to evidence their impact using outcome measures.

These measures might include: patient care outcomes – dying in the preferred place of care; quality outcomes – experience of care; clinical performance outcomes – wound care (NHS Bridgwater, 2015). Outcomes may be identified as part of a pathway demonstrating a staged approach to achieving patient-centred outcomes.

There are a wide range of well-documented ways to record Patient Reported Outcome Measures (PROMs); these can evidence the impact of health care on a patient's health and support the patient's perspective. PROMs can be generic as measured in a quality of life tool eg, EuroQo or EQ-5D, or specifically more patient-centred such as a specific health outcome, for example pain (RCN, 2010).

## 14. Caseload management: capacity, acuity, complexity

The complexity and scope of CCN services is often poorly understood (Parker et al., 2006; Pontin and Lewis, 2009; Carter et al., 2012; RCN, 2014). CCN work encompasses multiple challenging issues which are compounded by:

- the diversity of different CCN service configurations employed nationally
- advances in medical technology that enable children to receive increasingly complex, life-sustaining health care at home
- the ongoing government agenda to provide more care at home (Department of Health, 2011; RCN, 2014).

Contemporary CCN caseloads are therefore ever evolving, dynamic domains, ranging from basic injections and dressing changes to highly complex packages of care for children with long-term ventilation and other invasive health care needs (Carter and Coad, 2009; RCN, 2014). Unfortunately, there is a paucity of literature that captures both the scope and complexity of the CCN caseload whilst also offering a means of managing this effectively.

Effective management tools can be used to ensure that caseloads are reasonable and manageable in size, highlight risks and issues and support the best use of scarce resources (QNI, 2009). Yet, currently, there are no universally agreed effective caseload management systems available to support

staff with this crucial element of their work (QNI, 2014; RCN, 2014). Perhaps because the challenges presented by such work are complex and disparate. The RCN (2013) cites the recommendation of 20 WTE community children's nurses as a minimum per 50,000 children is difficult to quantify and requires adjustment to reflect the specific case mix, range of service provided and available skill mix (as well as the commissioning arrangements at local level) to ensure safe and effective staffing.

To support the ongoing growth of the CCN caseload and activity, whilst measuring acuity and capacity, systems are needed to measure the productivity of the team consistently. In Wales, the Nurse Staffing Levels (Wales) Act 2016 was introduced and, whilst a paediatric acuity and dependency toolkit is now available for paediatric inpatients, the work stream for community children's nursing remains at early stages. However, this work will use the underlying national triangulation principles to determine staffing levels to include patient acuity to estimate the amount of care each patient requires, compared to the numbers of nurses, quality indicators and, lastly, professional judgement. The Health and Care (Staffing) (Scotland) Act 2019, when implemented, will also include new legislative duties around the provision of community children's nursing across Scotland.

### **Caseload management in community children's nursing: an action research project, Mulcahy (2015) (unpublished)**

A local service development project was undertaken using action research methodology with the aim of developing an effective, caseload management tool. Action research offers a practical, collaborative approach to professional enquiry that is rooted in practice and strives to problem solve through reflection and cyclical re-evaluation of action: Observe – Reflect – Plan – Act – Repeat (Bowling, 2014; O'Leary, 2013). In this action research project, data was generated through a series of six, monthly focus groups using the skill and experience of a small, generic CCN team.

Evolving versions of caseload management tools were evaluated and re-designed to make them fit for purpose. This resulted in a dependency-complexity matrix and caseload monitoring tool (See appendices 5 and 6). The complexity score can then be reflected in a patient database, highlighting an individual patient's 'complexity' scores. The research identified: the need to articulate clinical risk effectively; the crucial and legitimate role of professional judgement in identifying patient dependency and complexity; the value of triangulating caseload information to facilitate comprehensive and robust caseload management.

Exposing the complexity of their caseload allows the CCN team to demonstrate factually and transparently what their professional judgment indicates. This knowledge allows the team to critically review the scope of the caseload to highlight risks and support effective and equitable caseload management decisions. It also supports escalation of issues to management and commissioners where necessary.

Further work is needed to explore the validity and potential transferability and adaptation of these tools throughout the UK, and adoption at a local level and associated use by CCN teams; this is evolving work and new 'risk' categories have now been added following feedback.

## 15. Conclusion

This RCN guidance highlights the evolving landscape of contemporary CCN services and its challenges, but recognises the opportunity for the innovative development of services in managing community children's nursing care across the four domains identified by the Department of Health (2011). Those working within and leading this field of practice need to understand the challenges and be responsive to this evolving health system. Key issues include: policy drivers, workforce, technology, financial consideration, and the widening health needs of

CYP. There is also an increasing need for safe and comprehensive CCN provision closer to home, supporting health care provided by the acute sector.

Identifying key elements will require UK-wide consideration and will enable consistent care delivery and service provision, but local adoption of such factors should remain to ensure the needs of the CYP population are met. By applying a futureproofing approach across the UK, CCN services will be fit for purpose in the future.

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# Appendix 1: Chronology of policy and campaigns

Author/title	Country	Date	Key messages
Ministry of Health <i>The welfare of children in hospital: the Platt report</i>	England	1957	<ul style="list-style-type: none"> <li>Children should not be admitted to hospital if it can possibly be avoided.</li> </ul>
House of Commons Health Select Committee <i>Health services for children and young people</i>	England	1997	<ul style="list-style-type: none"> <li>All children requiring nursing should have access to a CCN service staffed by qualified children's nurses wherever they live.</li> <li>This service should be available 24 hours a day, 7 days a week.</li> <li>Every GP should have access to a named community children's nurse.</li> </ul>
Department of Health/ Department of Education and Skills <i>National service framework standard 6: children and young people who are ill</i>	England	2004	<ul style="list-style-type: none"> <li>Children and young people who are ill should receive timely, high quality and effective care as close to home as possible.</li> </ul>
Welsh Assembly Government <i>National service framework for children, young people and maternity services in Wales</i>	Wales	2005	<ul style="list-style-type: none"> <li>A CCN service supports the child's right to care at home and reduces avoidable hospital admissions.</li> </ul>
Royal College of Nursing <i>A child's right to care at home</i>	All four countries	2009	<ul style="list-style-type: none"> <li>Every child has a right to expect care to be provided at home unless they need to be admitted to a hospital environment.</li> <li>Appropriate help and support from a CCN team should be available for parents/families to enable them to care for their child at home.</li> </ul>
Royal College of Nursing/ WellChild <i>Better at home campaign</i>	All four countries	2009	<ul style="list-style-type: none"> <li>Timely, high quality and effective care to be delivered in the home where possible.</li> <li>Packages of care should be provided which co-ordinate health, social care and education in a way that meets the individual and ongoing needs of the children and their families.</li> <li>Greater financial investment in children's nurses to work specifically with this group of vulnerable children and bridge the gap between hospital and community services.</li> </ul>
Department of Health <i>NHS at home: children's community nursing services</i>	England	2011	<ul style="list-style-type: none"> <li>Currently, few local community children's nursing services are able to meet the needs of all ill and disabled children and young people.</li> <li>CCN services are the bedrock of the pathways of care for these groups of children.</li> <li>Identification of what safe and sustainable CCN services look like.</li> </ul>

Author/title	Country	Date	Key messages
Department of Health, Children and Young People Outcomes Forum <i>Recommendations to improve children and young people's health results: independent report</i>	All four countries	2012	<ul style="list-style-type: none"> <li>The NHS and social care have been designed around the system rather than the individual; the system feels fragmented to children and young people and their families who have to tell their story repeatedly, striving to be heard and get the joined-up care they need.</li> <li>Designing and planning health and health care round the needs of the individual child or young person, taking account of their changing needs over time, will improve their experience of the service and their health outcomes – not just at a point in time, but for the longer term – and improve their lives enormously.</li> </ul>
Royal College of Nursing <i>Moving care to the community: an international perspective</i>	All four countries	2013	<ul style="list-style-type: none"> <li>A whole system approach is needed to effectively shift care out of hospitals and provide these services in the community. Nurses play a pivotal role in supporting and promoting better co-ordinated care.</li> <li>Where integrated care models have been successful, there is evidence to show that close collaboration between local authorities, commissioners, service providers and frontline staff have been instrumental in that success.</li> <li>Investments must be made to strengthen the community nursing workforce and priority must be placed on enabling and supporting nurses through education, training and developing leadership skills to ensure the right nurses with the right skills are leading the way.</li> </ul>
Royal College of Nursing <i>The future of Children's Community Nursing: the challenges and opportunities</i>	All four countries	2014	<ul style="list-style-type: none"> <li>This document looked at the role of the community children's nurse and models to support the care of children closer to home. Community children's nursing teams should have the right skill mix to support children at home this may require a blend of appropriate skills.</li> </ul>
Royal College of Paediatrics and Child Health <i>Facing the Future: Together for child health</i>	All four countries	2015	<ul style="list-style-type: none"> <li>Standards to support unscheduled care and encourage the right care in the right place for children with mild to moderate illness. Support for care closer to home.</li> <li>Standards include: <ul style="list-style-type: none"> <li>- each acute general children's service is supported by a community children's nursing</li> <li>- service which operates 24 hours a day, seven days a week, for advice and support, with visits as required depending on the needs of the children using the service.</li> <li>- there is a link community children's nurse for each local GP practice or group of GP practices.</li> </ul> </li> </ul>
Queen's Nursing Institute <i>The QNI/QNIS Voluntary Standards for Community Children's Nurse Education and Practice</i>	All countries	2018	<ul style="list-style-type: none"> <li>The standards have been developed to reflect generic community nursing teams where CCNs have leadership responsibilities and are designed to serve as a starting point to support discussion and planning as localities, regions, countries and HEIs look to further develop community children's nursing services.</li> </ul>

# Appendix 2: Lone worker risk assessment tool

Name of child		
Address		
Tool completed by	Date	
<b>Individual risk</b>	<b>Yes</b>	<b>No</b>
Do you know the child and family?		
Do you have access to a lone working device that connects to a response system? i.e Guardian 24		
Do you have a trust mobile phone or personal mobile phone?		
Is it safe to leave medicines/equipment at location?		
Will you be carrying any medicines/equipment which could make you a target for theft?		
<b>Physical environment risk</b>		
Are there any pets at the location?		
Is this visit in a geographical area that presents a specific risk to the lone worker?		
Is this visit in a block of flats which may restrict quick exit routes?		
Is there parking in close proximity to the address?		
Is the address remote or likely to have poor phone reception?		
Is the visit outside day light hours? Or at a weekend?		
<b>Social risk</b>		
Are there significant safeguarding concerns/social care involvement? Current or historical?		
Is there a known history of domestic violence?		
Is there a known history of drug abuse?		
Is there a known history of violence and aggression?		
Are individuals known to smoke at the address/location of the visit?		
Where pets are present, consider the specific safety of the child/young person and the ability to move to a place of safety in the event of the pet becoming aggressive, resulting in the child's safety being compromised. Consider the physical health needs and age of the child, type of pet, for example,an aggressive breed of dog.	Advice given	
	Yes	No

Comments:

Risk category	Action
	<p><i>CCN is required to carry out routine task in normal working hours</i></p> <p>The CCN must:</p> <ul style="list-style-type: none"> <li>Ensure all relevant information on location, patient, working procedures is available</li> <li>Ensure that the vehicle used for work is in a suitable condition and is road worthy.</li> <li>Ensure that they have a mobile phone and access to Guardian 24</li> <li>Ensure that they know what to do in an emergency and who to contact.</li> </ul>
	<p><i>If a child and family triggers a Red category:</i></p> <p>The CCN must:</p> <ul style="list-style-type: none"> <li>Ensure all the above actions are met and discuss each situation with their line manager and wider team.</li> <li>Consider whether the family merits a joint visit.</li> <li>Consider if there are significant risks and whether the family can be met in a mutual setting.</li> </ul> <p>Or</p> <ul style="list-style-type: none"> <li>If significant risk the CCN is unable to visit.</li> </ul>

(Note: risk assessment held electronically or ability to complete electronically.)

Community Children's Nursing Team: Bristol Royal Hospital for Children, University Hospitals Bristol NHS Foundation Trust

# Appendix 3: Community children's nurses home assessment tool



## Community children's nurses home assessment tool

Clinical guidance to assessing children – to be used in addition to clinical expertise

	Green signs Low risk No action/give appropriate advice/plan next CCN visit	Amber signs Intermediate risk Medical team/CNS advice or GP attendance	Red signs High risk 999 or Immediate ED attendance
<b>AIRWAY</b>	<ul style="list-style-type: none"> <li>Airway patent (including use of adjunct)</li> </ul>	<ul style="list-style-type: none"> <li>Wheeze</li> <li>Stridor</li> </ul>	<ul style="list-style-type: none"> <li>Airway compromised</li> <li>Airway obstructed</li> <li>Foreign body</li> </ul>
<b>BREATHING</b>	<ul style="list-style-type: none"> <li>Normal breathing pattern</li> </ul>	<ul style="list-style-type: none"> <li>Nasal flaring</li> <li>Subcostal recession</li> <li>Head bobbing</li> <li>Intercostal recession</li> <li>Tracheal tug</li> </ul>	<ul style="list-style-type: none"> <li>Grunting</li> <li>Sternal recession</li> <li>Poor respiratory effort due to exhaustion</li> <li>Silent Chest</li> <li>Too breathless to complete sentences or eat and drink</li> </ul>
	<ul style="list-style-type: none"> <li>Normal colour of skin lips and tongue</li> </ul>	<ul style="list-style-type: none"> <li>Pallor</li> <li>Clammy</li> </ul>	<ul style="list-style-type: none"> <li>Ashen</li> <li>Blue</li> </ul>
<b>CIRCULATION</b>	<ul style="list-style-type: none"> <li>Normal skin turgor</li> </ul>		<ul style="list-style-type: none"> <li>Reduced skin turgor</li> </ul>
	<ul style="list-style-type: none"> <li>Well perfused</li> <li>Normal colour for child</li> <li>Warm peripheries</li> </ul>	<ul style="list-style-type: none"> <li>Mottled</li> <li>Cold peripheries</li> </ul>	<ul style="list-style-type: none"> <li>Cap refill <math>\geq 3</math>secs (combined with other Amber or Red signs)</li> </ul>
	<ul style="list-style-type: none"> <li>Moist mucous membranes</li> </ul>	<ul style="list-style-type: none"> <li>Dry mucous membranes</li> </ul>	
	<ul style="list-style-type: none"> <li>Adequate fluid intake</li> <li>Adequate urine output/wet nappies</li> </ul>	<ul style="list-style-type: none"> <li>Reduced fluid intake</li> <li>Reduced urine output/ wet nappies</li> <li>Diarrhoea</li> </ul>	<ul style="list-style-type: none"> <li>Amber signs of dehydration plus lethargy and/or unresponsiveness</li> <li>Sunken fontanelle</li> </ul>
<b>DISABILITY</b>	<ul style="list-style-type: none"> <li>Alert</li> <li>Responding normally to social cues</li> <li>Normal Sleep</li> </ul>	<ul style="list-style-type: none"> <li>Responds to voice</li> </ul>	<ul style="list-style-type: none"> <li>Severe bleeding</li> <li>Responds to pain</li> <li>Unresponsive</li> </ul>
		<ul style="list-style-type: none"> <li>Confusion</li> </ul>	<ul style="list-style-type: none"> <li>Confusion (combined with other Amber or Red signs)</li> </ul>
	<ul style="list-style-type: none"> <li>No pain</li> <li>Mild pain</li> </ul>	<ul style="list-style-type: none"> <li>Moderate pain</li> </ul>	<ul style="list-style-type: none"> <li>Severe pain</li> </ul>
			<ul style="list-style-type: none"> <li>Neck stiffness</li> <li>Seizure</li> </ul>
	<ul style="list-style-type: none"> <li>Mobilizing normally</li> </ul>		<ul style="list-style-type: none"> <li>Focal neurological signs</li> </ul>
<b>EXPOSURE</b>	<ul style="list-style-type: none"> <li>No reports of pyrexia</li> <li>No flushing</li> </ul>	<ul style="list-style-type: none"> <li>Temp <math>\geq 38</math>C in baby under 3months</li> <li>Temp <math>\geq 39</math>C</li> </ul>	<ul style="list-style-type: none"> <li>Febrile Neutropenia (Temp <math>\geq 38</math>C and Neuts <math>\leq 1</math>)</li> </ul>
			<ul style="list-style-type: none"> <li>Severe burn</li> </ul>
	<ul style="list-style-type: none"> <li>No obvious rashes</li> </ul>	<ul style="list-style-type: none"> <li>Blanching rash</li> </ul>	<ul style="list-style-type: none"> <li>Bulging fontanelle</li> <li>Non-blanching rash</li> </ul>
	<ul style="list-style-type: none"> <li>No signs of anaphylaxis</li> </ul>		<ul style="list-style-type: none"> <li>Signs of anaphylaxis</li> </ul>



## Community paediatric early warning (PEW) score and physiological ranges for children

### Child's age 0 to 3 months

PHYSIOLOGICAL PARAMETERS	4	2	1	0	1	2	4
Respiration Rate	≤20	21-30		31-60	61-70	71-90	≥91
Oxygen Saturations	≤91%		92%-94%	≥95%			
Respiratory Distress				None	Mild	Moderate	Severe
Temperature	≤35°C			35.1-38°C	38.1-39°C	39.1-40°C	≤40.1°C
Systolic BP	≤50	51-60		61-80	81-90	91-110	≥111
Heart Rate	≤100	110-110	111-120	121-150	151-170	171-180	≥181
Capillary Refill Time				0-2 secs		≥3 secs	
Level of Consciousness				A/S		V	P or U

### Child's age 4 to 11 months

PHYSIOLOGICAL PARAMETERS	4	2	1	0	1	2	4
Respiration Rate	≤20	21-30		31-50	51-60	61-80	≥81
Oxygen Saturations	≤91%		92%-94%	≥95%			
Respiratory Distress				None	Mild	Moderate	Severe
Temperature	≤35°C			35.1-38°C	38.1-39°C	39.1-40°C	≤40.1°C
Systolic BP	≤60	61-70		71-90	91-100	101-110	≥111
Heart Rate	≤80	80-90	91-110	111-150	151-170	171-180	≥181
Capillary Refill Time				0-2 secs		≥3 secs	
Level of Consciousness				A/S		V	P or U



### Community paediatric early warning (PEW) score and physiological ranges for children

#### Child's age 1 to 4 years

PHYSIOLOGICAL PARAMETERS	4	2	1	0	1	2	4
Respiration Rate	≤10	11-15	16-20	21-40	41-60	61-70	≥71
Oxygen Saturations	≤91%		92%-94%	≥95%			
Respiratory Distress				None	Mild	Moderate	Severe
Temperature	≤35°C			35.1-38°C	38.1-39°C	39.1-40°C	≤40.1°C
Systolic BP	≤70	71-80		81-100	101-120	121-130	≥131
Heart Rate	≤60	61-70	71-90	91-130	131-150	151-170	≥171
Capillary Refill Time				0-2 secs		≥3 secs	
Level of Consciousness				A		V	P or U

#### Child's age 5 to 11 years

PHYSIOLOGICAL PARAMETERS	4	2	1	0	1	2	4
Respiration Rate	≤10	11-15	16-20	21-30	31-40	41-50	≥51
Oxygen Saturations	≤91%		92%-94%	≥95%			
Respiratory Distress				None	Mild	Moderate	Severe
Temperature	≤35°C			35.1-38°C	38.1-39°C	39.1-40°C	≤40.1°C
Systolic BP	≤80	81-90		91-110	111-120	121-130	≥131
Heart Rate	≤60	61-70	71-80	81-120	121-130	131-150	≥151
Capillary Refill Time				0-2 secs		≥3 secs	
Level of Consciousness				A		V	P or U



## Community paediatric early warning (PEW) score and physiological ranges for children

### Adolescent's age >12 years

PHYSIOLOGICAL PARAMETERS	4	2	1	0	1	2	4
Respiration Rate	≤10		11-15	16-25	26-30	31-35	≥36
Oxygen Saturations	≤91%		92%-94%	≥95%			
Respiratory Distress				None	Mild	Moderate	Severe
Temperature	≤35°C			35.1-38°C	38.1-39°C	39.1-40°C	≤40.1°C
Systolic BP	≤90	91-100		101-130	131-140	141-150	≥151
Heart Rate	≤50	51-60	61-70	71-100	101-120	121-130	≥131
Capillary Refill Time				0-2 secs		≥3 secs	
Level of Consciousness				A		V	P or U

### Issues of note:

- SBAR report a score of 4 to the child/young person's medical team/CNS and/or escalate to GP, ED or call 999 and request an ambulance.
- To be used alongside the community children's nurses home assessment tool.
- For patients who have modified physiological parameters, a score is not given provided that the measured observations are within the target parameters. Observations outside of modified parameters require escalation as appropriate considering clinical condition.
- Children under 3 months old OR any child with a central line with a temperature of ≥38C score 4 and require assessment.
- The community PEW tool is based on the BRHC in-patient PEW tool – September 2017. Temperature parameters have been adapted for community patients in order to trigger earlier escalation.

### Respiratory distress

- MILD - Nasal flaring / Subcostal recession / Wheeze
- MODERATE – Head bobbing / Intercostal Recession / Inspiratory or Expiratory Noises / Tracheal Tug / Grunt
- SEVERE – Sternal Recession / Exhaustion / Impending Respiratory Distress

### Level of consciousness

A = Alert S = Normal Sleep V = Only responds to voice P = Only responds to pain U = Unresponsive



**ACTION**

- If red or amber signs are triggered please do observations using the Community Paediatric Early Warning tool.
- A combination of Amber signs may equal immediate ED attendance/999 call.
- SBAR report any concerns to the child/young person's medical team/CNS and/or escalate to GP, ED or call 999 and request an ambulance.

**SBAR Communication Framework**

<b>Situation</b>	<ul style="list-style-type: none"> <li>• Your name/designation</li> <li>• Patients name/age</li> <li>• Where you are calling from</li> </ul>
<b>Background</b>	<ul style="list-style-type: none"> <li>• Brief medical history</li> <li>• Treatment to date</li> <li>• Reason for visit</li> </ul>
<b>Assessment</b>	<ul style="list-style-type: none"> <li>• Assessment of Airway, Breathing, Circulation, Disability, Exposure</li> <li>• Use tool overleaf</li> </ul>
<b>Recommendation/ Read back</b>	<ul style="list-style-type: none"> <li>• What have you done for the patient?</li> <li>• State your recommendations</li> <li>• Ask clinician for advice or further direction</li> </ul>

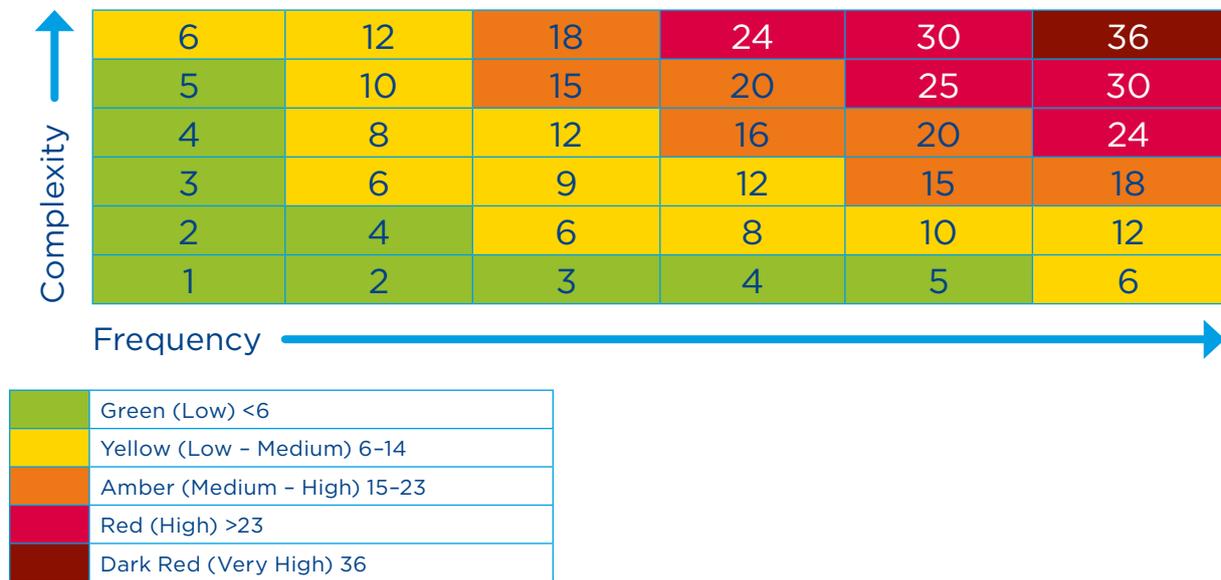
# Appendix 4: Community nursing RAG contingency

Service	Fully established Services provided	15% absent staff Services provided	30% absent staff Services provided	50% absent staff Service provided
Children's continuing care	<ul style="list-style-type: none"> <li>• Management of fully established care package provision</li> <li>• Provision of on call service</li> <li>• Management of new continuing care assessments and re-assessments</li> <li>• Competency training</li> <li>• Monthly auditing of records</li> <li>• Safeguarding – core groups, conference and strategy meetings</li> <li>• TAC &amp; CHIN meetings</li> </ul>	<ul style="list-style-type: none"> <li>• Management of health continuing care provision</li> <li>• Safeguarding – core groups, conference and strategy meetings</li> <li>• Provision on call</li> <li>• Management of new continuing care assessments</li> <li>• Competency training</li> <li>• TAC and CHIN meetings</li> </ul>	<ul style="list-style-type: none"> <li>• Management of health continuing care reduce service in accordance to priority requirements within pathway</li> <li>• Safeguarding – core groups, conference and strategy meetings</li> <li>• New competency training</li> </ul>	<ul style="list-style-type: none"> <li>• Management of health continuing care reduce service in accordance to priority requirements within pathway</li> <li>• Safeguarding – core groups, conference and strategy meetings</li> </ul>
Service	Fully established Services provided	15% absent staff Services provided	30% absent staff Services provided	50% absent staff Service provided
Community children's nursing team	<p>Full caseload management: Provision of community and clinic services</p> <ul style="list-style-type: none"> <li>• Acute/ambulatory <ul style="list-style-type: none"> <li>- Wound care</li> <li>- Sleep studies</li> <li>- IV medication</li> <li>- Sample taking</li> </ul> </li> <li>• Long-term conditions <ul style="list-style-type: none"> <li>- Reviewing and assessing oxygen dependent children</li> <li>- Cytotoxic therapy</li> <li>- Blood sampling and line care</li> <li>- Review and assessing -</li> </ul> </li> <li>• Palliative and end of life care</li> <li>• Training</li> <li>• Health care plans in schools and early year settings</li> <li>• Safeguarding – attending strategy meetings core groups and case conferences</li> <li>• Attendance at TAC meetings</li> </ul>	<p>Full caseload management: Provision of community and clinic services</p> <ul style="list-style-type: none"> <li>• Acute/ambulatory <ul style="list-style-type: none"> <li>- Wound care</li> <li>- Sleep studies</li> <li>- IV medication</li> <li>- Sample taking</li> </ul> </li> <li>• Long-term conditions <ul style="list-style-type: none"> <li>- Reviewing and assessing oxygen dependent children</li> <li>- Cytotoxic therapy</li> <li>- Blood sampling and line care</li> <li>- Review and assessing -</li> </ul> </li> <li>• Palliative and end of life care</li> <li>• Training</li> <li>• Health care plans in schools and early year settings</li> <li>• Safeguarding – strategy meetings, case correspondence, core groups</li> <li>• Attendance at TAC and CHIN meetings</li> </ul>	<p>Management of acute episodes requiring assessment and treatment (including hospital discharge)</p> <ul style="list-style-type: none"> <li>• Acute clinic (reduced clinic)</li> <li>• IV medication</li> <li>• Wound care</li> <li>• Cytotoxic therapy</li> <li>• Blood sampling and line care</li> <li>• Palliative care (not end of life)</li> <li>• Telephone review of caseload with medical interventions at home i.e oxygen dependency, weaning of medication</li> <li>• Safeguarding – case conferences, strategy meetings</li> </ul>	<ul style="list-style-type: none"> <li>• Cytotoxic therapy</li> <li>• Blood sampling and line care</li> <li>• Palliative care (not end of life)</li> <li>• Recent hospital discharge reviews to prevent re-admission/ children with acute episode requiring assessment and treatment</li> <li>• Safeguarding – case conferences, strategy meetings</li> </ul>

# Appendix 5: Community children's nursing caseload dependency - complexity matrix

The community children's nursing (CCN) caseload complexity matrix is intended to demonstrate nursing need through identification of the frequency of intervention and the duration and complexity of nursing care intervention(s) undertaken. The final score is achieved by plotting the frequency of nursing intervention against the complexity of intervention:

## Caseload scoring matrix



### Notes regarding use of the matrix:

The scores identified are a guide only and can be interpreted by the individual practitioner to support their final score for each specific child. There will not be a category that directly aligns with every patient and knowledgeable, pragmatic professional judgement should be used to determine appropriate scoring in relation to other patient scenarios. The matrix is based on a stepped approach so where nursing care needs exceed the level described there is a need to 'step up' the level to a maximum of Level 5.

The highest Level 6 is reserved for the most complex End of Life (EOL) scenarios or where highly complex children and young people (CYP) are discharged home with Long term Ventilation and other complex care needs that necessitate the nurse being in the home for > 3 hours/day. It is expected that this high level of intervention will reduce rapidly in the first week home

If the nursing team identify that a CYP's needs are at a certain level but not specifically identified in the descriptor they should consult with colleagues to agree a peer ratified score. Such further detail can be added to the descriptor to aid future assessment.

The timings identified are applied to the nursing task and any underpinning organisation e.g. arranging prescriptions and do not include travel time and note writing.

Children and young people should be scored for their most acute, nursing intervention first then any additional needs added on such as training, safeguarding, complex discharge planning, social & emotional support, etc.

This matrix is intended to be an evolving tool and changes will be made to best meet local practice needs.

## Community children's nursing caseload dependency – complexity matrix

### Frequency descriptor:

Score	Descriptor
1	6 – 12 monthly review Or once/twice acute intervention with no ongoing nursing needs
2	3 – 6 monthly nursing intervention
3	1 – 3 monthly nursing intervention
4	2 – 4 weekly nursing intervention
5	weekly nursing intervention
6	> weekly nursing intervention

## Community children's nursing caseload dependency - complexity matrix

### Complexity descriptor

Score	Approximate time for nursing Intervention	Description
1	20-40 mins	Basic nursing intervention with minimal additional nursing intervention beyond 1-2 visits: <ul style="list-style-type: none"> <li>• Simple suture removal</li> <li>• Basic wound management (dressings)</li> </ul>
2	20-45 mins	Basic nursing intervention with low level ongoing commitment to essentially, stable, nursing care management: <ul style="list-style-type: none"> <li>• Longer term dressings (e.g. pilonidal sinus)</li> <li>• Monitoring vital signs for children on certain medications (steroids, propranolol)</li> <li>• Subcutaneous or intramuscular injections (hormone injection for precocious puberty, heparin post clot)</li> <li>• Peripheral bloods for disease management (INR)</li> <li>• Support with enteral feeding supplies</li> <li>• Support with long-term stoma care</li> <li>• Support with long-term bowel and bladder management</li> <li>• Support with long-term eczema management</li> </ul>
3	30-60 mins	Lengthier nursing intervention > 30 mins duration with moderate/maintenance level of on-going nursing support and liaison with the MDT: <ul style="list-style-type: none"> <li>• Management/risk assessment of C/YP with naso-gastric tube</li> <li>• Central line management including taking blood samples and liaison with tertiary centre</li> <li>• Administration of bolus IV medication e.g. cytarabine</li> <li>• Administration of methotrexate and associated disease management support including peripheral bloods and organising prescriptions</li> <li>• Support and monitoring for oxygen dependent C/YP</li> <li>• Stable, long-term airway support/risk assessment; long term ventilation (invasive and non-invasive), tracheostomy, naso-pharyngeal airway</li> <li>• Annual review of nursing needs including equipment and consumables e.g. Out of Area C/YP</li> </ul>

4	60-90 mins	<p>More complex nursing intervention approximately 60 mins duration with high level of MDT liaison to manage care:</p> <ul style="list-style-type: none"> <li>• IV infusions</li> <li>• Complex dressing e.g. using PICO pump</li> <li>• Newly discharged C/YP post op with underlying health needs e.g. new gastrostomy on child with neurodisability</li> </ul> <p>OR C/YP with multiple nursing needs requiring intervention e.g. child with gastrostomy and hormone injections</p> <p>OR C/YP scored at previous 2/3 level but with significant additional nursing intervention for any one of the following involving additional:</p> <ul style="list-style-type: none"> <li>• Active training and competency assessment package in progress to meet health needs e.g. training parents or carers</li> <li>• High activity safeguarding in progress/active</li> <li>• Complex social or emotional issues needing frequent CCN intervention</li> <li>• Other high activity active plan in progress e.g. transition, discharge etc.</li> </ul>
5	90-120+ mins	<p>Newly discharged complex care with high MDT liaison OR C/YP scored at previous level 3 with at least two additional nursing interventions :</p> <ul style="list-style-type: none"> <li>• Active training and competency assessment package in progress to meet health needs e.g. training parents or carers</li> <li>• High activity safeguarding in progress/active</li> <li>• Complex social or emotional issues needing frequent CCN intervention</li> <li>• Other high activity active plan in progress e.g. transition, discharge etc.</li> </ul> <p>OR C/YP scored at previous Level 4 with 1 of the above interventions</p>
6	> 180mins - 24/7	<p>Highly complex, active nursing management of evolving medical condition that is changing during the 24 hour period such as EOL Care including keyworking with the wider MDT and responding to evolving aspects of health, emotional and social well being</p> <p>This category may also include highly complex discharges with long term ventilation requiring nursing intervention for &gt; 3 hours/day to support and troubleshoot an evolving situation. C/YP in this category should be reduced to level 5 within the first week of discharge</p>

Jane Mulcahy: Interim Head of Children and Young People's Specialist and Community Nursing Specialist Practitioner in Community Children's Nursing, Sussex Community NHS Foundation Trust

# Appendix 6: Caseload monitoring tool

Date:	High + Dark red	High Red	Med Amber	Low + Yellow	Low Green	Total caseload
No. of CYP						
Admissions						
Discharges						

Specialist high-risk intervention/care	No. of C/YP
DNACPR/ACP	
Oncology	
EOL (active management e.g. last 3/12)	
Safeguarding: on child protection Plan	
Safeguarding: active intervention / enhanced care e.g. Family of concern, TAC	
Looked after child (LAC)	
Tracheostomy	
Invasive ventilation and tracheostomy	
Non-invasive ventilation	
NPA	
NGT	
Sub-cut methotrexate	
Daily IV intervention e.g. antibiotics or cytarabine administration	
Identified pressure damage	
Other: high risk/acuity clinical pressures/risks/issues:	

Vacancies	Band	Stage of recruitment
Long term sickness	Names	Action/Return to work plan
Activity performance contacts	Narrative	Actions
Budget pressures		Management measures
Pay	Non-pay	
Training and development	Reason for non-compliance?	Action taken/planned
<ul style="list-style-type: none"> <li>• PDP/Appraisal</li> <li>• Stat. Day</li> <li>• BLS</li> <li>• Child Protection</li> <li>• Other exceptions</li> </ul> <p><i>(present as figure eg 7/8 meaning 7 of 8 staff compliant)</i></p>		
Incidents	Themes/learning	Actions
Complaints	Managed by?	Learning/actions
Successes and celebrations		

Jane Mulcahy: Interim Head of Children and Young People's Specialist and Community Nursing Specialist Practitioner in Community Children's Nursing, Sussex Community NHS Foundation Trust

## Appendix 7: Special needs school nursing

Access to a specialist school nurse for children and young people with special educational needs is variable, with wide variation in models of provision across the UK<sup>1,2</sup> and much of the health care provided by school teaching support staff. There is no specific policy or guidance that covers meeting the health needs of children in special educational needs schools, except in Wales where a framework was published in 2018.<sup>3</sup> This uses the principles of the 'team around the child' with the special needs school nurse as the care co-ordinator whilst the child is in school.

A recent study commissioned by the Bradford District Achievement Partnership (DAP) used the *West Sussex Assessing Nursing Needs in Schools*<sup>4</sup> to assess the nursing needs of 3,151 pupils in 22 special educational needs schools in England and Wales. The schools were four areas: Bradford, Sheffield, South Wales and West Sussex. The assessment of nursing needs tool has five categories of need:

- complex and fluctuating health needs likely during the school day
- complex long-term health conditions
- everyday complex health care needs
- medicines safety
- partnership plus: safeguarding, looked after children, transitions and education and health care plans.

Each category includes a range of health needs with varying levels of nursing input required. The highest levels of nursing intervention or assessment are required by children in the top two categories of need.

The design of the study was agreed at a roundtable event involving health and local

authority commissioners, head teachers and senior nurses from five areas. The fifth area was unable to be included in the study at that time but added a case study to the final report.<sup>5</sup> Those areas that had not previously used the tool identified children's nurses with experience with children with special needs to be trained to use the tool to collect the data on each child in the nominated schools. The data was collected in the first half of the academic year 2018/19, anonymised, collated and sent to the project lead.

The project lead also gathered information on each of the five areas, including information relating to the nursing model provided in each area. There was wide variation in nursing provision from no access to nursing services, unless the school purchased these independently through an agency, to nurses based in schools during the school day. Three of the areas had nursing services provided from the local community children's services. Two areas had nurses allocated to schools, but not based in the schools and in one area, these nurses were not commissioned to provide direct nursing services.

In all schools within the study, there were significant numbers of children in the complex and fluctuating health needs category, which includes children with end of life needs and unstable health conditions. The category descriptor on the tool indicates that for these children special needs school nurses will provide interventions and support health support staff and liaise with a wide range of other specialists. However, the study showed that, except for the Welsh schools, school staff were trained to provide for these health care needs often with no previous background in health care. Similarly, there were high numbers of children with complex long term health needs, where the tool indicates the needs for special needs school

1 Moore G, McConkey R & Duffy M (2003) The role of the school nurse in special schools for pupils with severe learning difficulties, *International Journal of Nursing Studies*, 40; 771-779.

2 Children & Young People's Commissioner Scotland (2016) *How complex healthcare needs can be met in Scotland's schools* (accessed November 2019).

3 Welsh Government (2018) *A School Nursing Framework for Wales Part 2 - Nursing in Special Schools*.

4 T Ward (2018) *West Sussex Assessing Nursing Needs in Schools: a Commissioning and Workforce Planning Tool*

5 Williams C (2019) *Special Needs School Nursing Project: Assessment of Nursing Needs of Children in Special Needs Schools in Four Areas of England & Wales* (unpublished to date).

nursing interventions and nursing support for health support staff. All 22 schools had children in these two categories on their rolls, including children with continuing care packages, although these packages often did not include provision in schools.

Children who have needs in the other three categories all have a requirement for nursing interventions including the training of health care support staff in meeting the health needs of children with everyday health needs, provision of education relating to medicines administration and involvement in partnership plus work, including safeguarding, mental health support, transitions and education and health care plans. This last category included many children in all four areas, contributing significant workload for nurses supporting these schools.

The study showed that the role and number of nurses varied widely between areas, with many nurses employed term time only. The ratios of nurses to children varied between 1:88 and 1:135. The role comprises public health, local authority 'children with disability' and children's community nursing roles, as well as educator, co-ordinator, risk management and multidisciplinary team working.

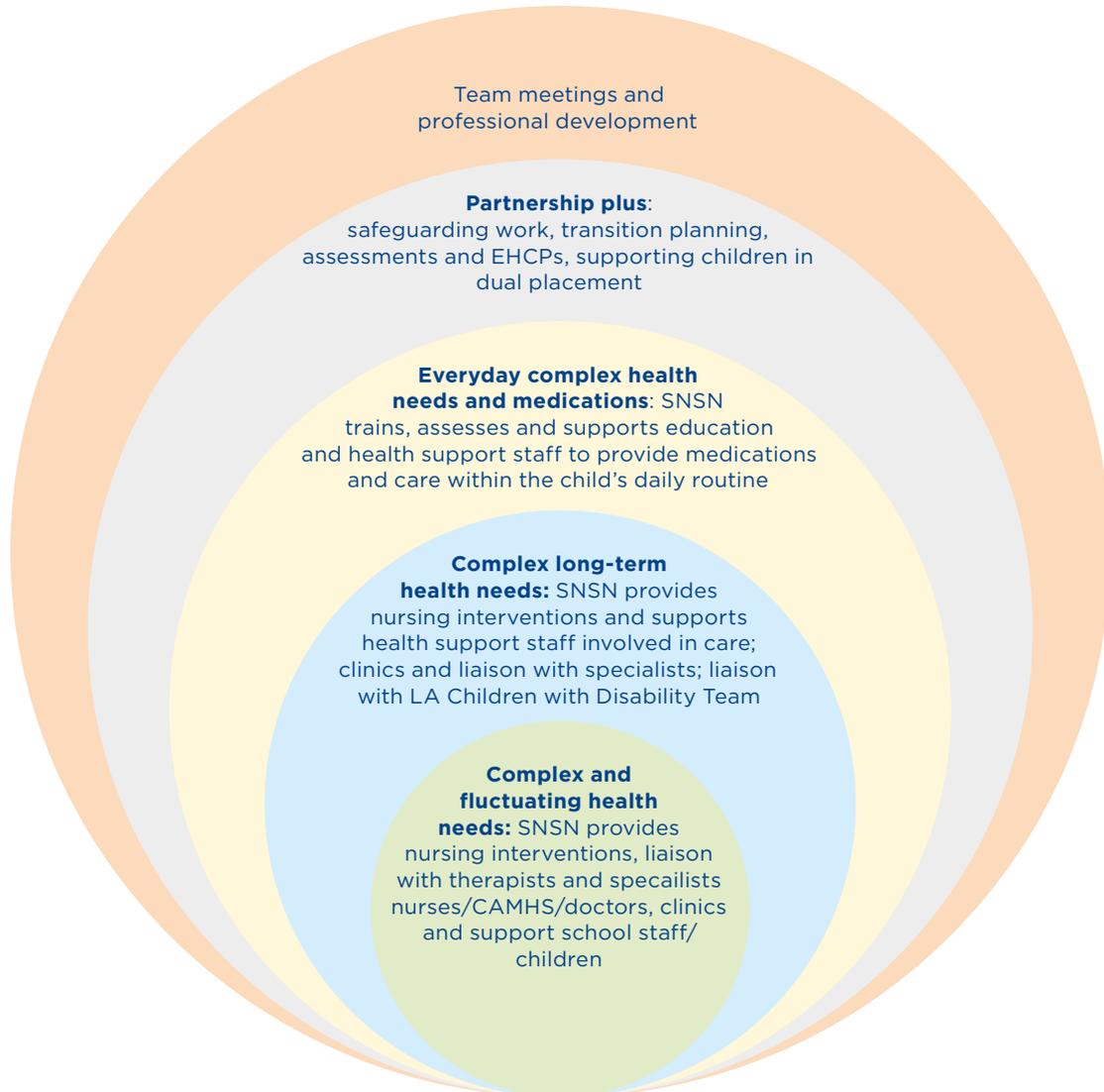
Education of school staff takes up a large proportion of the existing roles. The methods used to determine the number of school staff requiring training in each school varied from whole school training in common interventions to a small group of staff being trained in the more infrequent interventions required.

Whilst schools are trying hard to meet the health needs of their pupils, there appears to be significant inequity in health provision for this group of vulnerable children, whose numbers are continuing to grow, with school rolls increasing. However, children are unable to access the same standard of service in schools that they would receive either in the community or in health care settings. Whilst it is important not to medicalise special needs schools, it is important that children can access nurses skilled in meeting their health needs during the school day. The following model is recommended for the provision of special needs school nursing, with the study recommendations including provision of school nursing on site during the school day.

## Recommendations

- A model for health care provision is offered to ensure that children receive care that is appropriate for their needs and provided by people with appropriate knowledge and skills.
- A minimum of one SNSN should be based in every school where there are children with complex fluctuating and complex long-term health needs during school hours.
- The SNSN should be care co-ordinator for those children with nursing needs.
- There is a requirement for interdepartmental Government policy that specifically addresses the needs of this vulnerable group of children.
- A national, interdepartmental commissioning framework, based on current policy, is required to provide clarity and greater equality of health needs provision in special schools.
- The commissioning framework for this group of children should ensure that health needs are commissioned alongside educational provision.
- The commissioning framework should also include public health provision and take into account the local offer for children with disability in the local area.
- The Director of Children's Services should provide leadership in joint commissioning to ensure that public health, specialist health, social care and education needs are met.
- A multiagency approach to all aspects of the service, from commissioning to evaluation of services provided, is required to ensure that all needs are met.
- A joint governance framework is required to incorporate health, social care and education services, ensuring consistency of approach and shared learning
- Joint governance arrangements should be agreed to promote consistency in provision of health services
- There is a need for Continuing Care Panels to consider how health needs will be met in school

## Model for special needs school nursing



Carol Williams (author of *Special Needs School Nursing Project report*), November 2019

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