Core competencies for Paediatric Rheumatology Clinical Nurse Specialists and Advanced Nurse Practitioners

Administering disease modifying anti rheumatic drugs (DMARDs) and biologic therapies to children and young people with rheumatological conditions

Ruth Wyllie and Nikki Camina on behalf of BSPAR Section Council Nurse Group 2014

Introduction:

When caring for children and young people (CYP) with juvenile idiopathic arthritis (JIA), it is possible to have both specialist expertise and generalist expertise. The emergence of the Paediatric Rheumatology Clinical Nurse Specialist (CNS) and Paediatric Rheumatology Advanced Nurse Practitioner (ANP) and any national variations of these roles, along with the framework around DMARDs and biologic therapies, has highlighted the need to identify competencies. The overall management of CYP receiving DMARDs and biologic therapies should ideally be undertaken in a tertiary or secondary care setting, but home administration of subcutaneous injections is also recommended, combined with skilled paediatric specialist support. Nurses administering biologic infusions in a clinical environment should have easy access to specialist medical as well as CNS or ANP support.

Within the home environment, it is recommended that DMARD and biologic therapies administered by subcutaneous injection are administered whenever possible by either the patient, carer or guardian. This would be following a period of education and supervision by the CNS/ANP or their deputy.

The competency levels set out here will help to identify the range of skill mixes that can be used in providing CYP rheumatology care.

Skill mix:

The support needed to manage CYP receiving DMARD and/or biologic therapies includes:

- Teaching on disease management and therapies
- Pre-assessment
- Process and management during treatment
- Monitoring of treatment and disease
- On-going care.

As a CNS provides support and supervision, nurses who have a more basic knowledge of paediatric/CYP rheumatology, DMARD and biologic therapies can undertake some tasks. For this reason basic level competencies, as well as competencies for CNS are included.

Nature of the CYP department/unit:

Paediatric rheumatology departments may vary in a number of ways, for example:

- A large research unit with research practitioners and satellite units
- A department with dedicated day unit facilities
- A department with access to a planned investigation or medical day care facility
- A department administering biologic therapies within a ward environment or supporting a day care facility.
Supervision:

The competency framework in this document is intended for paediatric rheumatology CNS/ANPs and includes competencies for day care nurses, clinic nurses, and community nurses, who administer therapies, but have no overall responsibility for the on-going care of patients receiving DMARD and biologic therapies.

The defined network lead nurse will be responsible for supervision and training for nurses with minimal experience working in day care, clinic and community settings where patients receive DMARD and biologics therapies.

If no CNS/ANP support is provided in the day care unit, clinic or community setting, it will be the responsibility of the defined network lead nurse to ensure the provision of supervision and training for patients/parents/guardians in these areas. This may be completed by providing:

- Pre-assessment documentation for teaching and monitoring
- Information on the various biologics registries and research projects
- Data collection
- On-going management and follow up.

Educational materials to facilitate staff knowledge and skills updates, such as resource folders, and teaching sessions provided by the CNS/ANP should also be made available.

Competencies level 1:

CNS/ANP educated to degree standard or working towards a degree:

The CNS/ANP should be practising using a Trust policy document to support their practice. All CNS/ANPs responsible for the assessment and monitoring of treatment should have undertaken a period of study in, and/or feel confident that they have a detailed understanding of, the following areas:

- Inflammatory joint diseases
- The role of DMARDS, their side effects and monitoring
- The role of biologic therapies, their side effects and monitoring
- An awareness of local procedures to follow to apply for/acquire biological therapies, which includes baseline assessments, pre-testing for TB/chicken pox, antibody screening, chest x-ray and eligibility for treatments
- Monitoring the safe administration of therapies, including the development of therapies and procedures, basic life support, anaphylaxis support/awareness, consideration of the environments available for the safe administering of therapies and appropriate monitoring during infusions
- Understanding of cytotoxic policies and procedures (if required) relevant to Trust policies
- Proficiency in the administration and training of subcutaneous injections
- Identifying safeguarding or child protection issues; liaising appropriately with other agencies
- Up-to-date patient information literature and the use of a telephone helpline services
- Knowledge of functional assessments, in collaboration with physiotherapy and occupational therapy colleagues
- Pain management in chronic inflammatory disease
- Psycho-social and holistic support
- Co-ordination of a multi-disciplinary team support for patients
Management of the transitional care plans and be responsible for engaging with young people in preparation for transfer to adult teams
Being responsible for offering education and support in generic healthcare issue of adolescents and sign posting to relevant services where necessary
Awareness of cultural differences and impact upon disease management
Participation in the national BSPAR section council organisation to maintain up-to-date practice
Awareness and involvement in regional networks to enhance local knowledge and management of a patient group
Awareness of the management, assessment and therapeutic options for chronic pain (if appropriate)
Knowledge of NICE recommendations, RCN applicable documents, BSR registry outputs and other research studies as appropriate
The ability to be able to collect or facilitate accurate data for audit and research purposes
Recognition of the limits of their expertise and clinical competencies, and an ability to access appropriate clinical support.

If a CNS/ANP does not feel confident or does not have the relevant training in a particular area, this should be gained by working with a more experienced CNS/ANP in another area.

The CNS/ANP should also be competent in or have knowledge of:

- Educating and counselling patients and parents/guardians about DMARDs and biologic therapies. This includes providing appropriate up-to-date patient information
- Training patients/parents/guardians in the administration of subcutaneous treatments in a clinical or community setting, where appropriate
- Managing a telephone advice line service and providing information on for example, who should be contacted during out of normal service hours or in an emergency
- Providing ongoing health promotion by sign-posting patients/parents/guardians to appropriate resources to meet their needs e.g. for weight loss, smoking cessation etc.
- Statutory legal responsibilities of ensuring adequate documentation of care, including routine observations and follow-up care arrangements
- Joint assessment – this may be undertaken by physiotherapists within the MDT
- Routine assessment and screening of patients with chronic disease including interpretation of blood results, possible infections, exacerbation of disease, blood pressure, temperature and urine testing
- Providing clear and accurate processes for managing patients receiving intravenous infusions
- Relevant and current statutory training for emergency resuscitation and anaphylaxis procedures, where appropriate
- Prescribing of therapies if the CNS/ANP is a qualified nurse prescriber and permitted to do so according to local policy
- Managing nurse-led joint injection clinics and/or lists if qualified and permitted to do so according to local policy.

Level 1 nurses should be able to facilitate:

- The recognition of the CNS/ANP role within the multi-disciplinary team
- Ensuring all members of the team understand the limitations of their authority
• Ensuring that nursing practices are safeguarded when undertaking nurse-led initiatives
• The development and dissemination of patient information by providing regular updates
• Monitoring of the patients’ disease activity and outcomes
• Provision of care in safe, appropriately resourced environments, or reporting any resource deficits to senior management
• Training programmes for the multi-disciplinary teams and in external settings where other health professionals are administering biologic therapies to CYPs
• Access to 24-hour contact by families, by giving them the knowledge of who to contact and when, including out of hours services
• Ongoing health promotion by sign-posting patients, parents and guardians to appropriate resources to meet their needs e.g. for weight loss, smoking cessation etc.

Non-essential CNS/ANP knowledge and skills:

• The CNS/ANP may wish to develop local policies and training procedures for patients/parents/guardians to be trained in the self-administration of subcutaneous injections
• Cannulation and venepuncture skills
• Competence in managing patients receiving intravenous infusions via an infusion pump – the CNS/ANP may be required to support day care or clinic colleagues in providing care for patients
• Administering infusions, specialist nurses will not necessarily need to be competent in this area, but may choose or need to extend their skills in this in order to provide support for day care or clinic colleagues when needed.

Competencies level 2:

Ward or clinic nurse, in hospital setting and community practitioners:

This applies to nurses working in day care facilities, wards, or clinic settings, who administer infusions, but who have no overall responsibility for ongoing care of patients on DMARD and biologic therapies. These nurses need to be assessed as competent by the lead nurse for paediatric rheumatology or delegated deputy such as a ward/clinic manager. In some units, it may be appropriate to have a link nurse on the unit who can cascade relevant information and knowledge to the ward staff.

These nurses should have the following skills and knowledge:

• Basic rheumatology knowledge
• Knowledge of drug protocols and disease management
• Knowledge of safe cytotoxic administration, if appropriate
• Understanding of drug therapies
• Relevant and current statutory training and experience in the administration of intravenous infusions, emergency resuscitation and anaphylaxis procedures
• Where appropriate, have proficiency in teaching and training the patient/parent/guardian to administer medication in a clinical or community setting (according to local policy)
• Expertise in venepuncture and cannulation techniques is preferable but not essential
• Basic understanding of chronic disease management including the risks of immunosuppression and opportunistic infections
• Ability to recognise the need to seek specialist support if a patient highlights new issues that may affect treatment (for example, recent contact with chicken pox, changes in general health that may indicate problems, such as neurological problems)

• Undertaken basic training sessions in the management of rheumatology patients, including an awareness of painful joints and the appropriate siting of cannula, pain control, the use of joint protection and mobility issues

• Be aware of biologic therapies, mode of action, risks and benefits, and possible side effects at a basic level

• Understand the importance of assessment and management issues that form the total care of patients receiving biologic therapies

• Be aware of CNS/ANP support and how to access this

• Provide information on access to 24-hour care management for patients by providing information on who should be contacted out of normal service hours or in an emergency

• Provide ongoing health promotion by sign posting patients/parents/guardians to appropriate resources to meet their needs e.g. for weight loss, smoking etc.

• Awareness of cultural differences and sensitive to the specific needs of the individual.

**Competencies level 3:**

**Parents, carers, and as appropriate children and young people themselves:**

They should:

• After appropriate teaching with ongoing support be able to, if appropriate, administer therapies within defined protocols e.g. sub-cutaneous injections

• Be able to discuss the child’s medication and dose if required

• Have knowledge of safe practices in the administration and disposal of equipment

• Have basic knowledge of the disease and its management

• Be able to recognise any specific areas of concerns including pyrexia, signs of infection, drug reaction

• Be aware of the side effects of medication, how to identify these and the appropriate action to take

• Know whom to contact in case of any concerns

• Understand the importance of attending appointments for regular review and ongoing management.

The assessment of families, children and young people as competent to home-administer therapies requires considerable skill. CNS/ANPs based in a hospital setting should, if possible, link with community children’s nurses to draw on their considerable expertise in supporting the delivery of therapies in community settings.

When considering home administration, ensure that an adult trained in the safe administration of biological therapies supervises children and young people administering their own treatment; this could be the CYP’s parent or guardian.

Safety of drugs storage and equipment in the home is also an issue for consideration and should be covered as part of the education process.
A registered children’s nurse on part 8 or 15 of the NMC register must directly supervise any non-registered children’s nurses providing care and treatment to CYP. Trusts must identify a strategy to ensure that the CYP receive care and treatment from appropriately-trained personnel.

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This guidance document was ratified by the council of the paediatric and adolescent rheumatology section within the British Society for Rheumatology and is designed to support the delivery of paediatric and adolescent care in rheumatology.

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