



GIG
CYMRU
NHS
WALES

Grŵp Gweithredu
Afiechydon Prin
Rare Diseases
Implementation Group

Job Description and Person Specification **National Clinical Lead for Rare Diseases**

Author: Hywel Morgan, Manager, Major Conditions Implementation Groups

Date: 7.10.2021

Version: 4.0

Job Title:	National Clinical Lead for Rare Diseases
Grade:	As per current/substantive grade/salary of main employment
Hours:	0.2 wte (2 sessions per week)
Contract type:	2 year secondment appointment with option to extend for a further two year period by mutual agreement
Remuneration:	Via employing organisation, which will be reimbursed by the NHS Wales Health Collaborative
Directorate:	NHS Wales Health Collaborative
Department:	Major Conditions Implementation Group
Base:	TBC - River House, Gwaelod-y-Garth, Cardiff, CF15 9SS, or as agreed. Considerable travelling is expected across Wales as part of the role.
Accountable to:	Chair, Rare Diseases Implementation Group
Professionally Accountable to:	Relevant clinical/professional executive Director, Host Health Board
Managerially Reporting to:	Director, NHS Wales Health Collaborative

Job Description

1. Job Purpose Summary

As the National Clinical Lead, the post holder will work together with the Chair of the Rare Diseases Implementation Group (RDIG) and the Rare Diseases Implementation Group Coordinator to lead the strategic and operational development and delivery of coherent and effective network arrangements with partners across NHS Wales.

The post sits within the NHS Wales Health Collaborative which supports Health Boards and NHS Trusts in Wales through a work programme agreed with the Chairs and Chief Executives. Whilst the main responsibilities will be to the Rare Diseases Implementation Group, the post holder will be required to work flexibly to respond to the business needs of the Collaborative's work programme and with duties consistent to those described in this job description.

The National Clinical Lead for Rare Diseases will be expected:

- To provide professional and clinical leadership to RDIG;
- To provide specialist clinical advice to Welsh Government, health boards and constituent organisations of the RDIG in relation to the portfolio area;
- To represent RDIG at national, UK and international fora;
- To communicate RDIG and Welsh Government's vision around future health services in a way which motivates the clinical community based on improving outcomes within a value based context from national policy through to local delivery level;
- To inspire colleagues to innovate and problem solve acting in the best interests of the population and take collective responsibility for decision making;
- To lead the development of an Action Plan for Rare Diseases in Wales, which will set out how the priorities identified in the UK Rare Diseases Framework will be addressed in Wales.

2. Key Job Specific Responsibilities

Improving quality and outcomes

NHS Wales Health Collaborative	Rare Diseases National Clinical Lead JD & PS
--------------------------------	--

- To provide clinical leadership to, and on behalf of, the RDIG;
- To foster a culture of multi-professional engagement in the improvement of care across integrated pathways for Rare Diseases patients, this will include ensuring clinical colleagues are fully committed to the delivery of ambitious programmes of pathway redesign and quality improvement;
- To ensure involvement, influence and distributed leadership is promoted and available across the care system;
- To lead and oversee programmes of audit and quality assurance (such as Clinical Peer Review) which support individual professional development and also inform commissioner and provider organisations;
- To maintain credibility with all key players within the RDIG community, fostering a culture of collaboration for the delivery of equitable, high quality care across all sectors. At times this will include acting as an 'honest broker' reconciling conflicting views and interests;
- To understand, communicate and support the implementation of clinical policy relating to the RDIG;
- To promote a culture of innovation, developing and maturing strong partnerships across the Rare Diseases landscape.

Providing and enabling clinical leadership

- To ensure that clinical leadership is central to the delivery of all RDIG and NHS Wales activities;
- To work collaboratively across the NHS Wales matrix, particularly with WG, Health Boards and Trusts, General practice and primary care aligning policy with their delivery activities and ensuring mutual reinforcement of agendas;
- To provide guidance and direction for the Implementation Group Coordinator on clinical matters;
- To provide clinical leadership for the development and delivery of Implementation Groups activities across Wales;
- To provide leadership for service redesign and transformation;
- Identifying and working with the relevant individuals in the clinical leadership of the assigned area of work, e.g. appropriate professional groups, users and carers, key organisations, clinicians and network staff;
- To foster and promote a culture of clinical engagement and influence ensuring the RDIG is truly clinically led;
- To work with the RDIG Chair and Coordinator to create and maintain group structures and partnerships that support widespread multidisciplinary involvement including doctors, nurses, allied health professionals and clinical scientists;
- To meet regularly with colleagues across the health system;
- To provide visible clinical leadership for clinicians, other professionals, patients and citizens

Education

NHS Wales Health Collaborative	Rare Diseases National Clinical Lead JD & PS
--------------------------------	--

- To maximise the educational and training potential of the wider network in support of the agreed deliverables;
- To ensure good practice is disseminated; including training and education for primary care colleagues in the identification, prevention and management of Rare Diseases as required.

Contribute to Planning and Service Development

- To support the development and implementation of strategies, service change proposals and service improvement plans for the portfolio area;
- To work collaboratively to support implementation of key strategic plans/objectives and facilitate and drive forward improvement;
- Identifying new areas of development based on the needs of the local population and to support national and local priorities;
- Ensuring that effective delivery plans are in place for each development area agreed to be taken forward, including key outcomes to be achieved;
- To seek to ensure that a national approach is taken in configuration and planning for Rare Diseases services in Wales, whilst understanding regional differences;
- Ensure that the RDIG are fully integrated into national, regional and local planning processes;
- Ensuring that actions agreed as part of any service development are communicated to and carried out by constituent organisations where appropriate;
- Ensure progress reports are produced on a routine basis that provide the RDIG and key stakeholders with an overview of progress which includes highlighting successes and risks to delivery of objectives
- To support the RDIG in effectively fulfilling its role and remit, including ensuring that it is providing clinical advice and support as requested to contribute to the commissioning of safe and effective services;
- To provide clinical oversight to programmes of work to ensure they are achieving the best outcomes for the population and to evaluate and review their outputs;
- It is also expected that the post-holder will undertake appropriate leadership and development training if identified to support both their personal effectiveness and to help ensure the effective discharge of the various network functions as they become known in agreement with their host Medical Director and Director of the NHS Wales Collaborative.

2.1 Enabling patient and public involvement

- To act as a champion for patients and their interests and involve citizens and patients in the strategy development and decision-making of the RDIG;
- Work closely with Genetic Alliance UK and other third-sector organisations to ensure patient needs and views are adequately addressed.

2.2 Promoting equality and reducing inequalities

Date: 10/08/2021	Version: 1.0	Page: 4 of 11
-------------------------	---------------------	----------------------

NHS Wales Health Collaborative	Rare Diseases National Clinical Lead JD & PS
--------------------------------	--

- To uphold organisational policies and principles on the promotion of equality;
- To work with the Implementation Group Coordinator to create an inclusive working environment where diversity is valued, everyone can contribute, and everyday action ensure we meet our duty to uphold and promote equality.

2.3 Partnership, Engagement and Communication

- To represent the RDIG on national fora, providing a source of expertise and advice ;
- To engage and develop collaborations for clinical consensus and quality improvement across whole health communities, for the realisation of equitable access to quality care and the achievement of outcome ambitions for patients;
- To work with partners in support of aligning innovation, education, informatics and quality improvement;
- To work with national level bodies ensuring alignment of policy and service transformation for patients and improved outcomes;
- To ensure and promote partnership working including working with partner organisations/agencies to address identified need and known inequalities and in collaboration with others (including primary, secondary and tertiary care) to ensure services provided meet the needs of our combined population;
- Attendance at meetings with clinical teams, directorates and departments;
- To represent RDIG and Welsh Government at meetings outside of Wales in relation to the portfolio area;
- To champion and develop effective systems and processes for communicating and engaging clinical health economy partners and professions;
- To establish strong relationships and communication channels with clinical leads and professional colleagues to facilitate a two way dialogue to enhance the meaningful involvement of clinicians across Wales;
- To report regularly as required to the RDIG on the portfolio area and to clearly communicate decisions to clinical partners and other clinical stakeholders outside of the RDIG;
- To represent the network and actively contribute to relevant local, regional and national groups and discussions;
- To maintain effective and visible network communication arrangements with the clinical communities across Wales, that can be evidenced by strengthened and improved relationships, collaborative behaviors and joint working across and between teams, organisations and sectors.

2.4 Leadership for transformational change

- To be the clinical champion for the RDIG portfolio area;
- To model a collaborative and influencing style of working, negotiating with others to achieve the best outcomes;

NHS Wales Health Collaborative	Rare Diseases National Clinical Lead JD & PS
--------------------------------	--

- Embedding this approach across the network and the RDIGs support of strategic planning and transformational pathway redesign and change;
- To ensure that there is appropriate clinical engagement in RDIG activities within the portfolio area by promoting the benefits of clinical engagement of colleagues in service redesign and transformation;
- To develop and implement strategies, service change proposals and service improvement plans for the portfolio area including:
 - Working across the clinical community to identify and model areas of innovation and transformation based on the needs of the local population and to support national and local priorities;
 - Ensuring that effective plans are for each development area agreed to be taken forward, including key outcomes to be achieved;
 - Ensuring that progress reports are produced on a routine basis that provide the wider Implementation Group and key stakeholders with an overview of progress which includes highlighting successes and risks to the delivery of objectives;

2.5 Using insight and evidence for improvement

- To use insight in the use of evidence of analytics to inform improved outcomes and quality improvement;
- To promote the systematic application of quality framework tools such as NICE Quality Standards and methodologies to support understanding variation and drive system change.

2.6 Developing an excellent organisation

- To support the organisation's ways of working, model and it's values;
- To ensure compliance with all confidentiality and governance requirements within the NHS Wales Collaborative;
- To adhere to relevant professional codes of conduct.

2.7 Key Result Areas

- The RDIG clinical leadership responsibilities are clearly recognised and valued across Wales and the group adheres to appropriate policy and practices across all activities ;
- Partnership and shared responsibility is assumed in the shaping and delivery of the annual work plan and clinical input to the development of all Rare Diseases work plans;
- Recommendations for the reconfiguration of clinical services are based on objective, coherent and reliable information relating to the evidence base, clinical activity, quality and performance;
- Education and research are given a focus. Relationships are established and maintained through collaborative working and building working relationships with established professional organisations and academic departments;

NHS Wales Health Collaborative	Rare Diseases National Clinical Lead JD & PS
--------------------------------	--

- Effective communications are maintained, ensuring that the RDIG and its constituent organisations are actively engaged in the work of the Implementation Group;
- Appropriate development and clinician consensus of clinical guidelines and treatment protocols.

2.8 Assignment and Review of Work

The post holder will work with a high degree of autonomy and assignment of work will be largely self-directed, working with the RDIG Chair, Coordinator and Implementation Groups Manager within agreed objectives. Reviews will be carried out by the RDIG Chair, Manager and the NHS Wales Health Collaborative Director.

3. Physical skills and effort

Frequent VDU use is required for this post for periods of up to half a day in order to produce complex reports and analysis to support deadlines e.g. producing a programme business case which will make the case for investment in the programme of work as well as explain the programme approach – this may often be complex and require explaining in a way that a diverse audience can understand.

There is a frequent requirement to sit in a restrictive sitting position for up to 5 hours on a regular basis to meet the travelling requirements of the post.

Requirement to carry laptop computer and/or projection equipment (approx 3kg) to meetings for presentation purposes and carrying of laptop computer to facilitate flexible working (i.e. working from non-HQ venues and/or when travelling by train).

Keyboard skills are required for completing reports, documents etc.

4. Responsibility for patient/client care

Whilst not having specific patient/client care responsibilities, the post holder will:

- assist and respond to enquiries from members of the public/external organisations;
- be expected to assist with members of the public/external organisations e.g. in the event of an outbreak, emergency situation or at attendance of events/external locations.

5. Responsibility for Information resources

The post holder will:

- determine the resources, expertise and activities required to implement the programme through the most cost effective routes;
- provide advice on and promote the introduction of technology and information systems to support the promotion and uptake of quality improvement;
- use a wide range of IT applications to create reports;
- ensure security of records in line with Data Protection Act;

Date: 10/08/2021	Version: 1.0	Page: 7 of 11
-------------------------	---------------------	----------------------

NHS Wales Health Collaborative	Rare Diseases National Clinical Lead JD & PS
--------------------------------	--

- produce regular reports identifying performance against programme briefings;
- provide a source of intelligence on programme activities as part of everyday work;

6. Freedom to act

The post holder will:

- act as lead specialist ;
- demonstrate independence of thought;
- adopt a flexible approach to accommodate urgent or ad hoc requests;
- prepare for presentations at national, regional and local conferences;
- interpret national policy/guidelines for the programme e.g. interpreting and understanding that Welsh Government policy means for the programme;
- be responsible for own actions and those of line managed staff;
- identify issues and develop solutions where necessary and report to the RDIG;
- provide advice to senior officials on the development of policy;
- provide verbal and written reports as requested by Welsh Government officials, Networks, NHS Wales Health Collaborative Director and any others.

7. Mental effort

Periods of prolonged concentration are required when analysing information, scrutinising delivery/action plans, writing reports and formulating future strategies in conjunction with many competing priorities. These will require analysis and interpretation to understand the complications for the RDIG's overarching delivery plan and what corrective action may be required.

8. Emotional effort

Requirement to engage with and sometimes challenge clinicians, managers, and staff where barriers exist to implementation.

9. Working conditions

The post holder will work in office conditions and may be required to travel to meetings/events across Wales.

10. Competence

The post holder is responsible for limiting their actions to those that they feel competent to undertake. If the post holder has any doubts about their competence during the course of their duties they should immediately speak to their line manager.

11. Supervision

Where the appropriate professional organisation details a requirement in relation to supervision, it is the responsibility of the post holder to ensure compliance with this requirement. If the post holder is in any doubt about the existence of such a requirement they must speak to their line manager.

12. Risk management

It is a standard element of the role and responsibility of all staff of the Trust that they fulfil a proactive role towards the management of risk in all of their actions. This entails the risk assessment of all situations, the taking of appropriate actions and reporting of all incidents, near misses and hazards using the DATIX system.

13. Records management

As an employee of NHS Wales Health Collaborative, hosted by Public Health Wales the post holder is legally responsible for all records that they gather, create or use as part of their work within the Trust (including financial, personal and administrative), whether paper based or on computer. All such records are considered public records, and the post holder has a legal duty of confidence to service users (even after an employee has left the Trust). The post holder must consult their manager if they have any doubt as to the correct management of records with which they work.

14. Health and safety requirements

All employees of the Trust have a statutory duty of care for their own personal safety and that of others who may be affected by their acts or omissions. Employees are required to co-operate with management to enable the Trust to meet its own legal duties and to report any hazardous situations or defective equipment.

15. Flexibility statement

The content of this job description represents an outline of the post only and is therefore not a precise catalogue of duties and responsibilities. The job description is therefore intended to be flexible and is subject to review and amendment in the light of changing circumstances, following consultation with the post holder.

16. Confidentiality

All employees of the Trust are required to maintain the confidentiality of members of the public (service users) and members of staff in accordance with Trust policies.

Person Specification

Qualifications		
Essential	Desirable	How assessed
<ul style="list-style-type: none"> Fully qualified in a professional clinical discipline Evidence of relevant Continuing Professional Development 	<ul style="list-style-type: none"> Academic publications/ Presentations Higher Degree Demonstrate involvement in and enthusiasm for developing capability for improvement and system leadership 	<ul style="list-style-type: none"> Application Document check
Experience		
Essential	Desirable	How assessed
<ul style="list-style-type: none"> Substantial clinical experience Expert practitioner within their own field Extensive experience in the provision of clinical Rare Diseases services Previous formal experience of clinical leadership within an NHS organisation Experience of leading, managing and implementing change Experience in audit, research and training 	<ul style="list-style-type: none"> Experience of working with senior management in affecting the development of strategy Experience of peer review in a clinical setting 	<ul style="list-style-type: none"> Application Interview References
Knowledge		
Essential	Desirable	How assessed
<ul style="list-style-type: none"> Knowledge of WG and NHS Wales policy context Specialist knowledge of national Rare Diseases policy, RDIG objectives, the UK Rare Diseases Framework 	<ul style="list-style-type: none"> Knowledge and clear insight into current challenges facing NHS Wales Evidence of health care research or innovative service developments 	<ul style="list-style-type: none"> Application Interview

Skills and Aptitude		
Essential	Desirable	How assessed
<ul style="list-style-type: none"> • Aptitude or potential ability to function at a Director level • Knowledge and ability to influence, direct, and if necessary challenge senior peers or managers within the Rare Diseases community and partners in the health economy in order to deliver change • Ability to negotiate and influence at all levels • Proven track record of team working and delivering on key pieces of work 	<ul style="list-style-type: none"> • Additional specialist knowledge and expertise e.g. advanced presentation and facilitation skills • IT/Informatics 	<ul style="list-style-type: none"> • Application • Interview • References
Personal Attributes		
Essential	Desirable	How assessed
<ul style="list-style-type: none"> • Establish and maintain credibility with the clinical community • Ability to lead others, think strategically and communicate vision effectively • Gravitas amongst peers • Able to significantly influence others across organisational boundaries, without any direct authority • Demonstrate commitment to improving care through the principles of change management • Flexibility and enthusiasm for working in an open and transparent manner • Commitment to good team working and relationships 		<ul style="list-style-type: none"> • Application • Interview

Other		
Essential	Desirable	How assessed
<ul style="list-style-type: none"> • Willingness and ability to travel 		<ul style="list-style-type: none"> • Interview