

## JOB DESCRIPTION

<b>JOB DETAILS</b>	
<b>Job Title</b>	Clinical Nurse Specialist - Inherited Cardiac Conditions (ICC) Sudden Death Coronial Project Co-ordinator
<b>Reports to</b>	SWGMSA Programme Manager
<b>Band</b>	Band 7
<b>Department/Directorate</b>	Clinical - Molecular Genetics/Specialist Services

<b>JOB PURPOSE</b>
<p>The post holder will have a specialist role in developing, embedding and supporting pathways that ensure equitable access to a genomics-driven clinical programme, specifically addressing the needs of families who have suffered sudden unexpected deaths (SUD) due to potentially genetic causes. This work will support the strategic development of the wider Inherited Cardiac Conditions service, facilitating streamlined and efficient care for patients and families with these conditions.</p> <p>The post holder will utilize skills of clinical expertise, leadership and education to help establish a seamless service for patients, carers and staff across the Peninsula region. Strong organisational, collaborative and administrative skills will be important in establishing this new pathway for the region. As this is a new initiative, the role will involve a significant component of service development and administration, alongside supporting clinical care.</p> <p>Clinically, the post holder will be responsible for arranging family consent and safe transport of samples for genomic testing. Throughout this they will draw on their knowledge of inherited cardiac conditions to provide advice and information to clinical colleagues and families. They will support families in considering consent for samples and testing and will arrange appropriate cardiac screening, working alongside cardiologists, clinical geneticists and genetic counsellors. This role will offer experienced practitioners the opportunity to use advanced communication or counselling skills, delivering supportive care to families at what is likely to be an especially sensitive time.</p>

<b>KEY RESULT AREAS/PRINCIPAL DUTIES AND RESPONSIBILITIES</b>
<p>The post holder will be hosted by Royal Devon University Healthcare Trust-Eastern Services with the following responsibilities:</p> <ul style="list-style-type: none"> <li>To oversee and work as part of a sector wide multidisciplinary team delivering the local element of a national pilot project to improve the management of SUD families. The postholder will work closely with the GMSA and the British Heart Foundation (BHF) national and regional leads to ensure seamless delivery across the Peninsula.</li> <li>To work with local coroners, coroner's officers and other relevant care teams in the sector to ensure appropriate sample collection and liaison with clinical services to deliver a standardised and holistic pathway for at risk families.</li> <li>To liaise with the Genomic Laboratory Hub to ensure samples are received and processed efficiently, and that delays to sample reporting are communicated to the families.</li> <li>Liaise with the lead ICC nurses in Exeter and other regional ICC services to improve links and to reduce work duplication between clinical genetics and cardiology services</li> <li>To work with stakeholders across the Peninsula region to design pathways for dissemination across the sector, working with GMSA education and training leads to develop and deliver a programme of education to support implementation.</li> <li>To participate in, and work within the guidelines of the Multi-Disciplinary ICC Team to support patients and their families affected or at risk of ICC's including, cardiomyopathies, inherited</li> </ul>

arrhythmias and aortopathies. This will include but not be limited to: providing support and advice, coordinating family screening and taking consent for genomic samples and/or testing.

- To provide psychological, social and cultural support to families following a sudden cardiac death and in some circumstances to patients diagnosed with a relevant inherited cardiac condition.
- To fulfil all tasks and work as part of a team. To meet the needs of the service, the post holder may be required to work in other areas as appropriate as directed by the line manager.
- To provide telephone follow up to offer support to patients and bereaved families following a cardiac event; liaising with other teams as deemed appropriate and in the event that there is ongoing concern about symptoms.
- Provide education in relation to this specialist area of care to nurses in training, other genetic counsellors and new team members and other healthcare professionals.

## KEY WORKING RELATIONSHIPS

No. of Staff reporting to this role: none

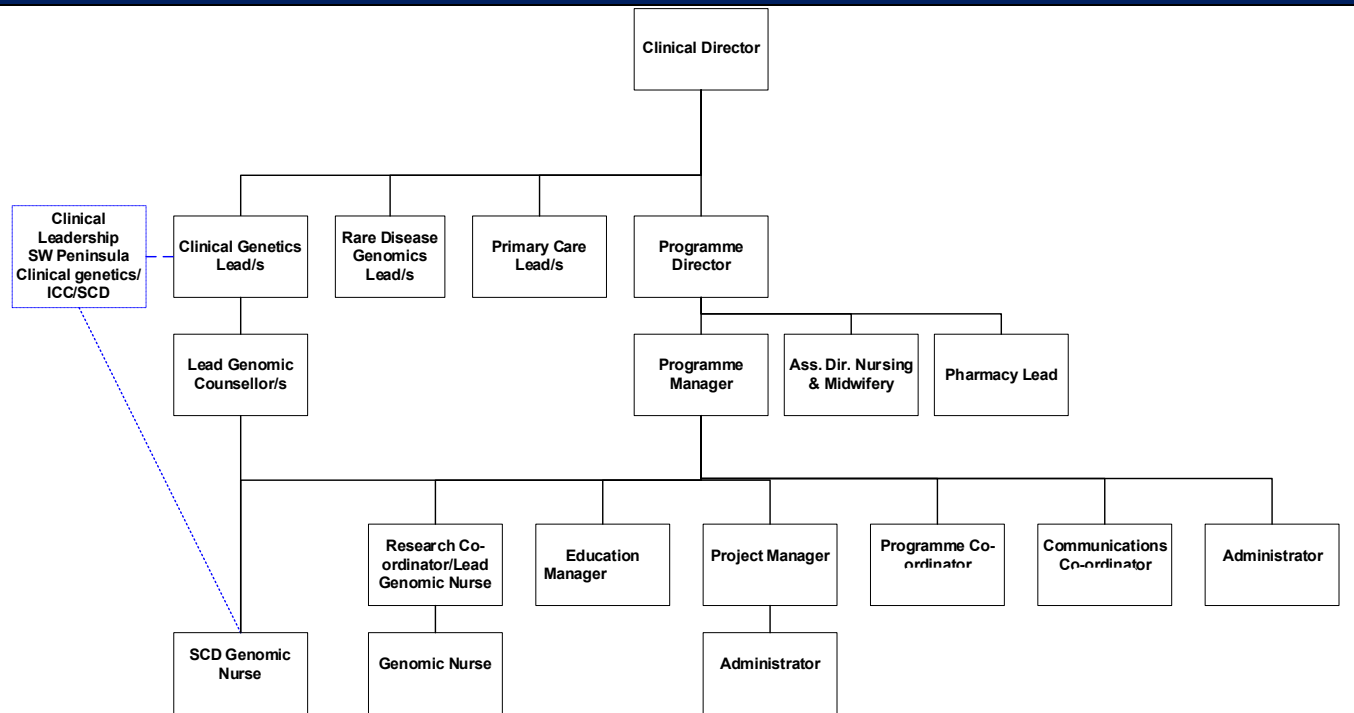
The post holder is required to deal effectively with staff of all levels throughout the Trust and region as and when they encounter on a day-to-day basis. In addition, the post holder will deal with the wider healthcare community, external organisations and the public. This will include verbal, written and electronic media.

The post holder will report to a line manager within the SW GMSA but will be clinically overseen by Consultants and senior clinical staff within the ICC service. Clinical supervision will be provided by a Consultant Clinical Geneticist alongside Consultant Cardiologist, both linked to the ICC service. In addition, the post holder will have additional support and guidance from Senior Genetic Counsellors within the regional Clinical Genetics service.

Of particular importance for this role are working relationships with:

Internal to the Trust	External to the Trust
<ul style="list-style-type: none"> <li>• SW GMSA Project Management Team</li> <li>• Clinical Genetics</li> <li>• Clinical Cardiology and ICC team (Exeter)</li> <li>• Exeter Genomics Laboratory</li> <li>• Pathology</li> <li>• ED and ICU</li> </ul>	<ul style="list-style-type: none"> <li>• Patients and families</li> <li>• Regional ICC clinical team members</li> <li>• Other Clinical Genetics services where there are shared families</li> <li>• Bristol genomics laboratory</li> <li>• Other Genomic Laboratory Hubs (GLH)</li> <li>• SWP Pathology Network</li> <li>• Coroner's office for coronial services in Devon and Cornwall</li> <li>• National Oversight board including British Heart Foundation (BHF)</li> <li>• Other charities such as CRY, SADS UK, cardiomyopathy UK</li> <li>• NHS England, NHS Improvement and Genomic Medicine Services Alliances (GMSA).</li> </ul>

## ORGANISATIONAL CHART



## FREEDOM TO ACT

- To be professionally and legally accountable for all aspects of own work, including the management of your patient case load and to organise efficiently with regard to clinical priorities and use of time.
- Make decisions within own professional role.
- To respond promptly to day-to-day operational challenges and take decisions on how to manage these.
- To ensure a high standard of clinical care for the patients under your management, and support more junior staff.

## COMMUNICATION/RELATIONSHIP SKILLS

- Communicate with families who are bereaved and provide support. Refer to primary care services or psychology, as required.
- Clearly communicate with families regarding cardiac risk for relatives and screening options to manage this.
- Sensitively explore options for genomic samples and testing, providing relevant and accessible information to support family decision making.
- Respond to emerging issues for the patient or family. This may include managing conflict within families created by sensitive processes or sensitive genetic information.
- Expertly communicate highly sensitive and potentially psychologically damaging information, which may cause high levels of distress
- Act as a role model, employ professional behaviour that encourages and wherever possible coaches other team members to challenge their current competencies.
- Proactively seek feedback from patients and their families on the standard of care they have received.
- Provide and receive complex and sensitive information, in accordance with information governance procedures, and in a professional and competent manner.
- Create action plans for areas of risk and poor performance, respond to DATIX incidents and complaints.
- Participate in the resolving of complaints and issues at a local level in partnership with patients, carers, their family and other health care professionals.

- Demonstrate excellent communication skills such as empathetic and reflective skills - especially when dealing with patients who are experiencing grief or disruption.
- Demonstrate effective, respectful communication when developing new services, managing working relationships across disciplines,
- The post holder will maintain links with local and national charities and self-help groups and make these services known to patients.
- Develop communications networks to enhance and support the patient experience.
- Uphold Royal Devon's shared values; promoting the corporate image of Northern Devon Healthcare NHS Trust to all individuals, groups and organisations both within the Trust and to the community at large.
- Communicate any alterations in service to the wider trust, ICS and relevant stakeholders.
- Demonstrate politeness, courtesy and sensitivity in providing compassionate care for patients, visitors/relatives and colleagues.
- To communicate effectively with patients and carers to minimise risk from ICC conditions and to ensure understanding of condition and treatment proposals.

### **ANALYTICAL/JUDGEMENTAL SKILLS**

- Assess the complex health, social and psychological needs of patients or families in a high stress situation and adjust care accordingly.
- Develop appropriate plans to support family recovery and reduce the likelihood of further cardiac disease or progression.
- Gather information regarding genetic analysis, family history or phenotype, work with clinical colleagues to incorporate this into the family assessment.
- Collect activity data and assist in its interpretation to develop or improve the service as applicable.
- Using assessment skills as well as clinical knowledge and judgement to determine when to seek specialist support and/or advice.
- Analyse and respond to complex clinical situations utilising specialist knowledge to assess a range of options to formulate solutions and recommendations.

### **PLANNING/ORGANISATIONAL SKILLS**

- Work proactively with different teams to tailor and embed a new pathway, within the given timeframe.
- Creation and monitoring of appropriate policies, protocols and standards for ICC services following an SUD.
- Receive and make referrals, in line with clinical guidelines.
- Work in collaboration with other agencies, including voluntary organisations and charities to enable to provision of support, resources, training and development of the service.
- Attend meetings relevant to the implementation and delivery of this service.
- Maintain up to date knowledge of contemporary themes and evidence in inherited cardiac conditions, anticipating any future need for service changes.
- Lead on projects relevant to the service as required.
- Work with Clinical leads to ensure that appropriate equipment and resources are available and appropriately maintained.
- Assist with the collation of clinical information that is not already in the Exeter EPR, but is needed for the accurate assessment of a family who have suffered a SCD or in some cases with other ICCs requiring regional ICC MDT review

### **PATIENT/CLIENT CARE**

- To be professionally and legally accountable for all aspects of own work, including the management of the patient case load and to organise efficiently with regard to clinical priorities and use of time.
- To provide spontaneous and planned advice, teaching and instruction to relatives, carers and other professionals, to promote understanding of the aims of the Sudden Cardiac Death programme, and to ensure a consistent approach to patient care across the whole Peninsula.

- To have a high level of autonomy when managing patients with cardiac conditions and be responsible for providing assessment and working with members of the ICC service to provide specialist treatment plans for patients with these conditions.
- Discuss with patient and carers the implications of genetic samples and genetic testing, supporting shared decision making on these topics.
- Ensure that clinical documentation is maintained to the Trust standard (including electronic records) and implement audits of records to measure and evaluate care planning.
- To act as patient advocate in line with the NHS plan and to actively apply in depth knowledge of holistic, socio-economic and cultural aspects of the care to clients within your specific speciality, acting as a role model and resource for patients, relatives and staff.
- Provide specialist advice, information and support to relatives/carers as appropriate, following consultation with members of the multi-disciplinary team and in line with service procedures and protocols.
- Ensure that all team members are suitably competent and qualified to complete the tasks required of their role.

#### **POLICY/SERVICE DEVELOPMENT**

- Support development and embedding of the regional pathway following a SUD. This will cover the storage of suitable DNA samples and family screening.
- Support the creation and review of treatment guidelines and operational policy within the ICC service.
- Have an excellent working knowledge of national and local standards and monitor own and others quality of practice as appropriate.
- Assess and manage clinical risk within all relevant work areas.
- Promote user involvement in the planning and evaluation of the service (including through audit), establishing links with relevant support groups and charities.

#### **FINANCIAL/PHYSICAL RESOURCES**

- Ensure that any equipment, furniture or building in need of repair is reported to the correct authority using recognised means.
- To ensure the safe use and care of equipment.
- Be able to report incidents and produce action plans.
- In conjunction with line manager identify, analyse and discuss cost pressures and financial constraints in a timely manner.

#### **HUMAN RESOURCES**

- To train, supervise, and provide education and support to junior staff, students and other members of the wider MDT.
- To provide educational presentations to primary and secondary care teams to increase awareness of ICC where required for pathway development.
- To be responsible for maintaining own competency to practice through CPD activities, and maintain a portfolio which reflects personal development.
- Maintain and develop current knowledge of evidence-based practice in the area of inherited cardiac conditions, developing specialist knowledge.
- Participate in the staff appraisal scheme and be responsible for complying with your agreed personal development programme to meet set knowledge and competencies.
- To be an active member of the in-service clinical supervision programme by the attendance and presentation at staff meetings, tutorials, training sessions, external courses and reflective practice.

#### **INFORMATION RESOURCES**

- To maintain accurate, comprehensive and up-to-date documentation, in line with legal and departmental requirements, and communicate assessment and treatment results to the appropriate disciplines in the form of reports and letters.

- Be actively involved in the collection of appropriate data and statistics for the use of the department / organisation.
- Undertake training for electronic information systems in place and under development.

### RESEARCH AND DEVELOPMENT

- Undertake the measurement and evaluation of your work and current practices through the use of evidence based practice projects, audit and outcome measures, either individually or with more senior colleagues.
- Benchmark the service against national standards and practice in other centres. Use audit data to identify areas for service improvement.
- To undertake as directed the collection of data for use in service audit and research projects. To manage and undertake research into specific areas of clinical practice and service delivery using a range of research methodologies as part of MDT audit and departmental research initiatives.
- Be actively involved in professional clinical groups, Peer Review Groups and other professional development activities.
- The post holder will show evidence of accessing clinical supervision for clinical and professional issues.

### PHYSICAL SKILLS

- Key board skills
- Highly developed physical skills to support venepuncture.

### PHYSICAL EFFORT

- There is occasional requirement for light physical effort for short periods e.g.- moving wheelchairs, educational resources
- There is a likely requirement to travel to other Trust sites and external venues to attend meetings and support ICC sites and pathology services outside of Exeter.

### MENTAL EFFORT

- Manage competing demands of providing services on a daily basis.
- Read, decipher & interpret patient information.
- Frequent mental effort in assessment and support programmes.

### EMOTIONAL EFFORT

- Frequently working with patients who may have poor prognosis, significant anxiety or emotional distress from recent bereavement
- Ability to deliver difficult news to patients and carers in a professional manner and continue to have a good relationship with the patient
- Work with patients and families with challenging behaviours.

### WORKING CONDITIONS

- Work in a variety of settings according to patient needs which on occasions may include the patient's own home which can involve hot/cold temperatures, cluttered environments and unhygienic conditions
- Travel to other locations for clinics, meetings, conferences or training events
- Use of visual display screen equipment.

### OTHER RESPONSIBILITIES

Take part in regular performance appraisal.

Undertake any training required in order to maintain competency including mandatory training, e.g. Manual Handling

## Contribute to and work within a safe working environment

You are expected to comply with Trust Infection Control Policies and conduct him/herself at all times in such a manner as to minimise the risk of healthcare associated infection

As an employee of the Trust, it is a contractual duty that you abide by any relevant code of professional conduct and/or practice applicable to you. A breach of this requirement may result in action being taken against you (in accordance with the Trust's disciplinary policy) up to and including dismissal.

You must also take responsibility for your workplace health and wellbeing:

- When required, gain support from Occupational Health, Human Resources or other sources.
- Familiarise yourself with the health and wellbeing support available from policies and/or Occupational Health.
- Follow the Trust's health and wellbeing vision of healthy body, healthy mind, healthy you.
- Undertake a Display Screen Equipment assessment (DSE) if appropriate to role.

## DISCLOSURE AND BARRING SERVICE CHECKS

This post has been identified as involving access to vulnerable adults and/or children and in line with Trust policy successful applicants will be required to undertake a Disclosure & Barring Service Disclosure Check.

## GENERAL

This is a description of the job as it is now. We periodically examine employees' job descriptions and update them to ensure that they reflect the job as it is then being performed, or to incorporate any changes being proposed. This procedure is conducted by the manager in consultation with the jobholder. You will, therefore, be expected to participate fully in such discussions. We aim to reach agreement on reasonable changes, but if agreement is not possible, we reserve the right to insist on changes to your job description after consultation with you.

Everyone within the Trust has a responsibility for, and is committed to, safeguarding and promoting the welfare of vulnerable adults, children and young people and for ensuring that they are protected from harm, ensuring that the Trusts Child Protection and Safeguarding Adult policies and procedures are promoted and adhered to by all members of staff.

At the Royal Devon, we are committed to reducing our carbon emissions and minimising the impact of healthcare on the environment, as outlined in our Green Plan available on our website. We actively promote sustainable practices and encourage colleagues to explore and implement greener ways of working within their roles.

# PERSON SPECIFICATION

<b>Job Title</b>	Clinical Nurse Specialist - Inherited Cardiac Conditions (ICC) Sudden Death Coronial Project Co-ordinator.
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Requirements	Essential	Desirable
<b>QUALIFICATION/ SPECIAL TRAINING</b>		
GCRB** registration as a Genetic Counsellor (must be maintained) <b>OR</b>	✓	
Successful completion of STP Programme in Genomic Counselling <b>OR</b>	✓	
Genetic Counsellor registration with a Board that has reciprocal arrangements with GCRB (see GCRB website for details) <b>OR</b>	✓	
Registered Nurse with relevant Cardiac Nursing qualification	✓	
Educated to masters level, or possesses equivalent demonstrable experience	✓	
<b>KNOWLEDGE/SKILLS</b>		
Ability to work within a multidisciplinary environment	✓	
Ability to work as a member of a team	✓	
Ability to manage own workload	✓	
Ability to work within supervision	✓	
Extensive verbal and written communication skills	✓	
Counselling skills	✓	
Good knowledge of genetics	✓	
Good report and writing skills	✓	
<b>EXPERIENCE</b>		
Teaching experience		✓
Knowledge of clinical governance	✓	
Experience of research governance		✓
Experience of literature searching and critical analysis	✓	
Experience of clinical audit	✓	
Experience of working with inherited cardiac conditions	✓	
<b>PERSONAL ATTRIBUTES</b>		
Excellent attention to detail and standards of care and thorough record keeping.	✓	
Highly motivated, flexible and enthusiastic	✓	
Excellent ability to work within and contribute to the development and maintenance of a highly skilled and motivated team	✓	
Ability to self-motivate and work autonomously	✓	
Awareness and respect for the needs and values of patients and professional colleagues	✓	
Commitment to further professional training	✓	
<b>OTHER REQUIREMENTS</b>		
Phlebotomy		✓
Knowledge and previous experience of using PC software, particularly word processing and databases.	✓	
The post holder must demonstrate a positive commitment to uphold diversity and equality policies approved by the Trust.	✓	
Ability to travel to other locations as required.	✓	

		FREQUENCY			
		(Rare/ Occasional/ Moderate/ Frequent)			
WORKING CONDITIONS/HAZARDS		R	O	M	F
<b>Hazards/ Risks requiring Immunisation Screening</b>					
Laboratory specimens	Y	x			
Contact with patients	Y		x		
Exposure Prone Procedures	N				
Blood/body fluids	Y	x			
<b>Hazard/Risks requiring Respiratory Health Surveillance</b>					
Solvents (e.g. toluene, xylene, white spirit, acetone, formaldehyde and ethyl acetate)	N				
Respiratory sensitisers (e.g isocyanates)	N				
Chlorine based cleaning solutions (e.g. Chlorclean, Actichlor, Tristel)	N				
Animals	Y	x			
Cytotoxic drugs	N				
<b>Risks requiring Other Health Surveillance</b>					
Radiation (>6mSv)	N				
Laser (Class 3R, 3B, 4)	N				
Dusty environment (>4mg/m3)	N				
Noise (over 80dBA)	N				
Hand held vibration tools (=>2.5 m/s2)	N				
<b>Other General Hazards/ Risks</b>					
VDU use (> 1 hour daily)	Y				X
Heavy manual handling (>10kg)	N				
Driving	Y			X	
Food handling	N				
Night working	N				
Electrical work	N				
Physical Effort	Y		X		
Mental Effort	Y				X
Emotional Effort	Y				X
Working in isolation	Y			X	
Challenging behaviour	Y		X		