



## National Health and Social Care Professions Office

### HSCP Representative: Role Requirements Checklist

Required Information	Comments
Name of the Group	Integrated Care Pathways for Rare Diseases Stakeholder Group
Purpose of the Group	Review and develop an agreed set of care pathways for rare diseases that will provide best practice guidance and support to patients, families and health care professionals
Chairperson/Lead of the Group	Geraldine Sweeney, Business Manager, NRDO, Acute Operations
Has there been HSCP involvement previously? If yes, please provide the name.	Not specifically via NRDO engagement however through Phase 1 development Clinical Leads were asked to map the preliminary care pathways onto existing Irish healthcare services and structures to develop optimal care pathways. The Clinical Leads at their discretion engaged with their MDTs and professionals from other disciplines for detailing of specific sections, where appropriate. This was not the case with all of the pathways.
<p>What documentation is available to inform someone taking up the role? We would appreciate a copy of the following:</p> <p>Terms of Reference Previous minutes Other relevant documents</p>	<p>Each member of the stakeholder group will receive</p> <ul style="list-style-type: none"> <li>- Terms of reference</li> <li>- Copy of 'Designing Rare Disease Care Pathways in the Republic of Ireland – a co-operative model', a publication recently submitted to the Orphanet Journal of Rare Diseases (publication in process)</li> </ul> <p>Additional supporting documentation will be provided ahead of the first meeting of the newly established Stakeholder Group.</p>
What is the proposed role of the HSCP representative?	To ensure adequate and appropriate inclusion and representation of all disciplines of Health Care Professions detailed as 'core components' in the individual care pathways



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What is the projected term for the HSCP representative?	Stakeholder engagement will be broken into two phases with each phase duration approx. three months each. This is subject to change depending on availability
How frequently are meetings held?	It is proposed that each phase will consist of 3-4 meetings. This includes the initial full stakeholder briefing meeting. Following the first briefing meeting, the project team will have discipline specific engagement meetings (approx 1-2 meetings) to review the care pathways and input / feedback from the relevant discipline / stakeholder
Where do the meetings take place and what is the expected duration of meetings?	Meetings will be organised online as virtual meetings via MS Teams. It is proposed meeting duration will be no longer than 1.5 hours
Is protected time agreed for attendance at meetings?	No
Is there an agreed arrangement re travel and subsistence for meeting attendance?	Not required
Is there a nominated contact person for any additional queries in relation to the Group?	Chairperson / Lead for Stakeholder Group and their designated project support
Any additional information	<p>This integrated care pathways project will focus on improving outcomes for people with a rare condition that requires multidisciplinary care and therapeutic interventions, through development of an effective universal care pathway model that can incorporate multiple health and social care professions. The care pathways will provide easy to follow guidance for diagnosis and multidisciplinary care suitable for GPs, Hospital specialists and health and social care professionals, patients and carers. The model will also assist in mapping and giving visibility to where care will be offered i.e. Hospital Specialist setting/ Primary care/Community care or a mixture of all.</p> <p>Patient representatives/advocacy groups were given an opportunity to contribute to the development of the pathways based on their experience of the diagnostic odyssey and their experience of living with a rare condition.</p>