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**National Clinical Programme for Rare Diseases**

**Criteria for Designation of Centre of Expertise in Rare Diseases –**

**Self Assessment Template** Application for: Full Membership

For all fields listed below please include additional information if relevant:

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| **Proposed Centre for Designation**Name of centre: Address:Hospital CEO/Manager:Hospital Group: | Primary contact:Name and contact details of current Director of Service or Co-ordinator:Please attach CV of this person. |
| Is centre stand-alone or co-located?Name and number of sites composing the Centre:If co-located, is it co-located with paeds, adult or maternity? Please specify. |
| What is catchment area of the centre in terms of population served? |
| Please list the 15 most prevalent conditions evaluated and treated at the Centre and describe the Thematic Group from the attached list (at end of this document). |
| Please list the names of all medical consultants providing services at the centre and the WTE they each provide to this service. |
| **Description of Total Activity: Paediatrics (up to 18 years)** |
| **Number of:** | 2011 | 2012 | 2013 | 2014 |
| New consultations |  |  |  |  |
| Follow up consultations |  |  |  |  |
| Inpatient admissions |  |  |  |  |
| Average length of stay of inpatient admissions  |  |  |  |  |
| Day case consultations |  |  |  |  |
| Outpatient consultations |  |  |  |  |
| Home visit consultations |  |  |  |  |
|  |
| **Description of Total Activity: Adult (18 years and older)** |
| **Number of:**  | 2011 | 2012 | 2013 | 2014 |
| New consultations |  |  |  |  |
| Follow up consultations |  |  |  |  |
| Inpatient admissions |  |  |  |  |
| Average length of stay of inpatient admissions  |  |  |  |  |
| Day case consultations |  |  |  |  |
| Outpatient consultations |  |  |  |  |
| Home visit consultations |  |  |  |  |
| Please describe what is the current waiting time for - 1) a new consultation:2) follow up appointment:3) in-patient admission:Additional information: |
| How many protected beds (if any) are available for the service? |
| Does the service provide emergency patient available advice? If yes, describe. |
| What is the evidence of capacity to produce good practice guidelines for national use? |
| Demonstrate a multi-disciplinary approach, integrating medical, allied health, psychological and social needs (e.g. RD board). |
| What is the evidence of capacity to adhere to good practice guidelines for diagnosis and care? |
| Are there quality management systems in place to assure quality of care, including National and European legal provisions? |
| Is there participation in internal and external quality schemes, when applicable? |
| Is there capability to propose quality of care indicators for each specific rare disease and implement outcome measures, including patient satisfaction initiatives. |
| What is the evidence for a high level of expertise and experience? Include:* Relevant publications from the Centre
* Evidence of national/international recognition
* Membership on European Boards/Committees
* State involvement in production of national guidelines/care pathways
 |
| What has the centre contributed to the scientific understanding of each disorder? |
| How many peer-reviewed publications relating to each disorder arose from the centre? |
| How many peer-reviewed grants supporting research into each disorder were awarded to the unit? |
| What teaching and training activities aimed at transferring knowledge about the disorder in question are in place? |
| What processes are in place to provide expert advice remotely? |
| What is the existing capacity to participate in data collection for clinical research and public health purposes? |
| What clinical trials of the disorder in question has the unit participated in? |
| Is the centre co-located with a Clinical Research Facility? |
| Does the centre lead, or participate in, a registry? |
| Which university is the unit affiliated with? |
| Demonstrate a multi-disciplinary approach, integrating medical, paramedical, psychological and social needs (e.g. RD board). |
| What systems are in place to assure the continuity of care between childhood, adolescence and adulthood, if relevant. |
| What systems are in place to assure the continuity of care between all stages for each disease?Please name the Adult Provider.  |
| For Paediatric Centres - is there a formalised transition arrangement with an adult provider? |
| Please indicate the number of cases that have been transitioned from the paediatric to adult setting in the year 2014. |
| Does the centre have satellite/out-reach centres. Please describe. |
| Please list the names of Orphan medications currently administered/monitored by the centre. |
| What links and collaborations are in place with other centres of excellence at national, European and international level? |
| What links and collaborations are in place with patient organisations (where they exist)? |
| What arrangements are in place for referrals within individual Member States and from/to other EU countries if applicable? |
| What innovations have been taken by the unit in the last 10 years to improve the delivery of care, and especially to shorten the time taken to reach a diagnosis? |
| Are any E-Health solutions in place in the unit (e.g. shared case management systems, expert systems for tele-expertise and shared repository of cases)? |
| **Please list WTE for the following staff members:** |
| **Staff member** | **Number of WTE** |
| Consultant |  |
| NCHD |  |
| SpR |  |
| CNS/ANP |  |
| Staff Nurse |  |
| Allied Health Professional |  |
| Medical Social Worker |  |
| Clinical Psychologist |  |
| Genetic Counsellor |  |
| Business Manager  |  |
| Other |  |
|  |
| Have any service cost savings initiatives been put in place in the last 2-3 years?If so, please outline. |
| Does the centre have a ring-fenced National Budget?Please indicate when the budget for the Centre was last reviewed by HSE: |
| Is there a National Governance Board for the Centre? Please describe. |
| Please add other points that might require national review. Specifically, please outline the 4 most relevant difficulties obstructing service delivery, if relevant. |
| Please outline 5 key recommendations to improve delivery of patient centred care for your Centre. |
| Please attach a resume of laboratory diagnostic facilities attached to the Centre with a list of diagnostic tests actually provided by the affiliated. |
| Free text for the Centre to add regarding vision or further comments: |

**Rare Disease Groups**

* Chromosomal disorders
* Single gene disorders
* Hereditary metabolic disorders
* Haemophilia and hereditary coagulation disorders
* Rare congenital disorders
* Rare endocrine disorders
* Neurological disorders and neurometabolic disorders
* Rare skin disorders
* Rare kidney diseases
* Rare eye disease
* Rare connective tissue/skeletal/autoimmune disorders
* Rare lung disorders including alpha-1-antitrypsin disorder
* Rare congenital heart and rhythm disorders
* GI/liver conditions

*Does not include rare cancers or CF*