National Clinical
& Integrated Care Programmes
Person-centred, co-ordinated care

ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND

Patient summary for transfer to an adult healthcare provider

The National Clinical Programme for Rare Diseases

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Building a
Better Health
Service

Seirbhís Sláinte
Níos Fearr
á Forbairt

Introduction

The National Clinical Programme for Rare Diseases (NCPRD) was established to ensure that the needs of people with a rare disease are recognised, understood and addressed in a coordinated and patient-centred way. The programme is a partnership between the HSE and the Royal College of Physicians of Ireland. As of September 2020 the functions of the NCPRD were operationalised and transferred to the National Rare Diseases Office (NRDO) within Acute Operations, HSE governance structures.

In July 2018 the NCPRD published a Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases. Leading on from the publication of this document, this template has been developed to assist with the transfer of young adults with rare diseases from paediatric to adult healthcare services.

Additional information and guidance

For more detailed recommendations about the transition of young people living with rare diseases please refer to the Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases, which is available on the website of the NRDO. A number of resources for healthcare providers are also available on the website (www.rarediseases.ie), including a summary version of the model of care and a guide for planning the transition of young people with a rare disease from paediatric to adult healthcare services.

The National Rare Diseases Office provides current and reliable information about rare diseases to patients, families and healthcare professionals. The office was established in 2015 by the HSE and is staffed by healthcare professionals who have significant experience working with people affected by rare diseases. The office can help to identify national and European experts in the management of specific rare diseases and also provides contact details for patient support groups and information about clinical research projects and European Reference Networks. The office can be contacted via email (rare.diseases@mater.ie) and by phone on (01) 8545065.

This is available as a Microsoft Word document so that it can be adapted locally.
Please contact the National Rare Diseases Office to request a copy: rare.diseases@mater.ie

[Insert hospital logo]

Summary of [patient name] under the care of [Consultant name] at [department/service and hospital name].

Department contact details:

PATIENT INFORMATION:

Place patient sticker here

Patient email:

____

Parent/guardian/carer name and contact information:

____
____
____

Name and phone number for emergency contact:

____

Relationship of emergency contact to patient:

____

Name and address of school/college:

____
____
____

Language(s) spoken and verbal communication ability:

____

Name of GP:

____

Address:

____
____

Tel No:

____

Special considerations (e.g. hearing impairment, pregnant, interpreter required, safety concern to self or others):

____
____
____

DIAGNOSTIC INFORMATION:

Diagnosis at time of transfer:

____

Age at which diagnosis was made:

____

Presenting signs and symptoms:

____
____
____

Tests completed to confirm diagnosis:

____
____
____

Genetic testing and/or counselling history:

____
____
____

Medical History (symptoms, medical procedures):

-
-
-
-

Previous surgical history (symptoms, surgeries):

-
-
-

Medications:

____
____
____
____

Vitamins and food supplements:

____
____
____

Allergies (including food allergies):

____
____
____

Compliance/adherence issues with treatments:

____
____
____

Other Dietary information:

____
____
____

Supplies/equipment required (e.g. home appliances, etc.):

____

____

____

Please describe most recent nursing intervention:

____

____

____

Most recent Physio/OT/Speech/Nutritional (or other) intervention:

____

____

____

____

____

Other health care professionals involved: Yes No
If yes please list name of:

Consultant(s) and speciality:

____

____

Hospital(s):

____

____

Date of next OPD:

____

Psychosocial considerations:

____

____

____

General health:

____

____

____

Reproductive health and education received:

____

____

____

If the patient has cognitive delay, have sexual health issues been addressed/initiated by the Youth Health Services? www.spunout.ie Yes No

Genetic testing:

Has the patient received genetic counselling? Yes No

Details:

____

____

____

Medical card:

Is the patient eligible for medical card/disability allowance? Yes No

Have applications for these been started/completed? Yes No

Details:

____

____

____

Occupation/education:

Current occupation or education programme:

____

Grade completed:

____

Living arrangements: (circle)

- Independently
- With family
- Care facility

Details:

____

____

____

Community supports:

Details:

____

____

Capabilities of daily living: (circle)

- Independent
- Needs assistance (specify)

Details:

____

____

____

Level of independence:

Task	Rating 1, 2 or 3*	Comments
Understands disease(s)		
Understands basics of treatment		
Makes/keeps appointments		
Success with self-management		
Prepares meals		
Monitors own medications		
Does own food shopping		

*Rating scale

1. Independent, able to complete task
2. Parent support required for activity or task
3. Dependent on parents and others for activity or task

Interests/recreation:

____

____

____

<u>MOST RECENT MEDICAL/DIAGNOSTIC TEST RESULTS:</u>

Test type	Result
1	
2	
3	
4	
5	

ATTACHMENTS:

Document/report	Notes/comments
1	
2	
3	
4	
5	

GENERAL ASSESSMENT OF TRANSFER READINESS:

____

____

____

____

____

____

____

____

____

PATIENT SUMMARY COMPLETED BY:

Name of MDT member	Date	Signature

Name: (Lead consultant for the patient)

____

Signature:

____

Date:

____