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

Version 1.0 January 2019

Building a Better Health Service | Seirbhís Sláinte Níos Fearr á Forbairt

Introduction

The National Clinical Programme for Rare Diseases 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.

In July 2018 the programme 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 a rare diseases from paediatric to adult healthcare services.

Additional information and guidance

For more detailed recommendations about the transition of young people living with a rare disease 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 National Clinical Programme for Rare Diseases. A number of resources for healthcare providers are also available on the website including a summary version of the model of care and a guide for planning the transition of young people with a rare diseases from paediatric to adult healthcare services.

www.hse.ie/eng/about/who/cspd/ncps/rare-diseases/resources

NRDO
National Rare Diseases Office

The National Rare Diseases Office provides current and reliable information about genetic and 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. The office also provides contact details for patient support groups and information about clinical research projects and European Reference Networks. The National Rare Diseases Office can be contacted via email rare.diseases@mater.ie and by phone (01) 8545065. www.rarediseases.ie

This document is available in Word format so that it can be adapted locally.
Please contact the National Clinical Programme for Rare Diseases to request a copy.
ClinicalProgrammeAdmin@RCPI.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:

_____

_____

_____

MOST RECENT MEDICAL/DIAGNOSTIC TEST RESULTS:

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:

_____