

Transition from children's to adult services across Europe

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Postal survey

- **18** countries responded (**July** 2015)

Key areas:

- **Dedicated inpatient facilities**
- **Adolescent specialist/transition nurses**
- **Age transition process commenced**
- **Issues affecting transition**
- **Joint policies and protocols**
- **Education of nurses**

Definition of 'transition'

'...the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult orientated health care systems'

(Blum et al 1993)

Countries that have responded

- **Austria**
- **Belgium**
- **Croatia**
- **Czech Republic**
- **Denmark**
- **France**
- **Germany**
- **Greece**
- **S. Ireland**
- **Netherlands**
- **Norway**
- **Portugal**
- **Serbia**
- **Slovenia**
- **Sweden**
- **Switzerland**
- **Turkey**
- **United Kingdom**

Countries not responded

- Armenia
- Cyprus
- Estonia
- Finland
- Hungary
- Iceland
- Italy
- Latvia
- Lithuania
- Luxemburg
- Malta
- Macedonia
- Poland
- Romania
- Slovakia
- Spain

Dedicated inpatient facilities

Yes = 5

Austria, France, Germany, Sweden, Switzerland

No = 9

Belgium, Croatia, Czech Republic, Greece, S Ireland, Norway, Serbia, Slovenia, Turkey

Variable = 4

Denmark, Netherlands, Portugal, UK

In Denmark there are dedicated inpatient facilities in some hospitals for adolescents

Only a few hospitals have wards for adolescents only (Portugal)

In the Netherlands there are dedicated inpatient hospital facilities for adolescents, although facilities differ per hospital

There are dedicated inpatient hospital facilities for adolescents, particularly within psychiatric ward areas where there are adolescent houses where a multidisciplinary team can help family and teenagers with an environmental approach (France)

No hospital facilities dedicated to an adolescent population nor are there joint clinics. Adolescents are either cared for in the service for children or in the service for adults (Belgium)

Most hospitals have dedicated non clinical areas which are for the exclusive use of young people. There are a few hospitals that have a designated adolescent ward, while many more have dedicated hospital bays or side rooms on hospital wards for adolescents (UK)

In Irish general hospitals with a paediatric department there are no dedicated inpatient hospital facilities for adolescents

Nurses that specialise in

Adolescent care

Yes = 7

Austria, Belgium, Germany, Greece, Sweden, Switzerland, UK

There are some specialist adolescent nurses, including at Nurse Consultant level (UK)

Nurses are trained and specialised in adolescent care, including adolescents (Belgium)

No = 9

Croatia, Czech Republic, France, S Ireland, Netherlands, Norway, Portugal, Serbia, Slovenia, Turkey

Some hospitals have clinical nurse specialists who are trained in the comprehensive care of patients with a specific condition i.e. congenital heart disease (Belgium)

Variable = 1

Denmark

The paediatric nursing education has content and training in adolescent care. (Portugal)

In the Netherlands pediatric nurses care for children from 0 to 18 years old. Some nurse work more with adolescents but there is no specialisation.

This is included in the specialist training for paediatric nurses (Sweden)

Nurses that specialise in

Transition

Yes = 6

Germany, Netherlands, Norway, Portugal, Sweden, UK

There are specific nurses to support the transition of adolescents to adult services. This is the case for adolescents with Cystic Fibrosis, but also in some other chronic diseases (Netherlands)

No = 10

Austria, Belgium, Croatia, Czech Republic, France, Greece, S Ireland, Serbia, Slovenia, Turkey

A few hospitals have specific nurses who support the transition from children's to adult services (Denmark)

Variable = 2

Denmark, Switzerland

A few paediatric hospitals have family nurse working methodology and nurses support this transition (Portugal)

There are liaison nurses for some groups like children and adolescents with chronic disease like diabetes, cardiac disease and rheumatism. Some of these nurses support the transition process (Norway)

The support is included in the care of chronically ill children (Sweden)

Nurse education

Undergraduate

Yes = 1

Portugal

No = 17

The nursing care of adolescents is part of paediatric nurse training (Czech Republic)

The principles of transitional care is not part of the core curriculum of undergraduate education programmes (Belgium)

The curriculum of pediatric nursing includes the adolescent period (Turkey)

Austria, Belgium, Croatia, Czech Republic, Denmark, France, Germany, Greece, S Ireland, Netherlands, Norway, Serbia, Slovenia, Sweden, Switzerland, Turkey, UK

Post-graduate

Yes = 1

Portugal

No = 17

In the frames of community (specifically school nurses) and paediatric nursing lectures students are informed in a limited level about transition care during their post-graduate studies (Greece)

Adolescent care is part of the basic training for Paediatric Nursing, the specific topic of “transition” is an increasing issue within the curriculum (Germany)

Austria, Belgium, Croatia, Czech Republic, Denmark, France, Germany, Greece, S Ireland, Netherlands, Norway, Serbia, Slovenia, Sweden, Switzerland, Turkey, UK

There is no specific education programme to support this important aspect of Paediatric care (S Ireland)

Although there is no specific post graduate education for nurses, nurses can access a University Degree with specialisation in adolescence (France)

Transition commences:

- **Before 12 years of age = 1** Serbia
- **12-14 years = 4**
Denmark*, Norway, Switzerland, UK
- **14-15 years = 2**
Belgium, Greece
- **15-16 years = 3**
Austria, Germany, Sweden
- **16-17 years = 1**
Netherlands
- **18 years = 8**
Austria, Croatia, Czech Republic, France, S Ireland, Portugal, Slovenia, Turkey

There is no formal policy about the age at which transition should start or have been completed (Belgium)

For young people with diagnoses such as diabetes and growth disorders the transition process generally begins at 18 years of age (Denmark)

At 12-14 years of age doctors and nurses gradually start to prepare the child in self management for example about their medication and consultation without parents (Belgium)

This is determined by local solutions. Within surgery, the age limit is often lower than in medical illness (Sweden)

Children after the age of 14 are treated as adults in general hospitals (Greece)

The individual situation and the developmental stage of the adolescent should however be considered (Germany)

Transition is not one event but should be a planned process over years as a way of supporting autonomy and responsibility for their own health care while at the same time allowing parents to step back (UK)

Adolescents are cared for in hospitals for children and adolescents until the age of 18, then they go to hospitals for adults (Germany)

In Denmark there are discussions about making transition programmes, transition plans, having dedicated nurses at the paediatric wards and the adult wards to facilitate a good transfer, but often things do not happen because of lack of time

A few hospitals also have a special café, which is a meeting place for adolescent to meet other adolescent (Denmark)

The actual transition age can be quite individual but is planned usually to coincide with the Leaving Certificate age in the Irish second level education system – this is usually age 17/18 years but can be 19 years of age in some cases (S Ireland)

In some cases of chronic diseases such as Cystic Fibrosis, Thalassaemia, Congenital Heart Diseases adolescents continue their treatment for a prolonged period in paediatric hospitals and then in adults hospitals (Greece)

There are a number of cases that non-profit organisations representing adolescents and their families have influenced the design of a new service based on adolescents' views and needs. For example the design of the new paediatric cancer hospital in Athens was based primarily in children's and adolescents needs and desires (Greece)

Transitions tend not to be properly planned and discussed with the family and patient (Denmark)

Adolescents are invited to contribute and advise staff how to plan a successful transition and how to meet the need from adolescent in general. An advisory panel based on the perspectives of adolescent is becoming a part of working with adolescents in Odense (Denmark)

Transitions are being carried out based on the age of the patient rather than based on an individual assessment. A smooth transition might be preferable (Denmark)

Obstacles to transition

- **Delayed start of transition process (2)**
- **Staff turnover (1)**
- **Lack of formal policy (4)**
- **Lack of architecture and facilities for adolescents (3)**
- **Lack of recommendations about transition (1)**
- **Lack of resources (4)**
- **No payment for nurses undertaking transition clinics (2)**
- **Organisational issues (3)**
- **Parents/young person relationship with paediatrician/paediatric staff (4)**
- **Lack of knowledge and education about adolescents, transition and congenital conditions (7)**
- **Different cultures and rules (3)**
- **Different approaches between children's and adult services (5)**
- **The adult service is sometimes in another hospital (2)**
- **Lack of cooperation and communication between the staff in children's and adult services (6)**
- **Lack of time (2)**
- **Lack of identified case manager/defined nursing role (4)**

Key issues

- **Informed about transition 2yrs in advance**
- **Detailed information about new centre**
- **Two way feedback from new centre**
- **Ambulance cooperation**
- **Attitudes of nurses**
- **Education of adolescents in self management & desire for transition to adult service**
- **Education of staff**
- **Education and support for parents**
- **Organisational issues**
- **Lack of investment in adolescent services**
- **Information exchange between children's and adult services**
- **Joint consultations between children's and adult physicians**
- **Financial and regulatory issues**
- **Organised transition service**
- **Need for designated nursing role and adolescent facilities**
- **A family visit to the adult unit/hospital an important introduction factor**
- **Communication and collaboration between children's and adult team**
- **Integrated information systems**
- **Shared philosophy between children's and adult services**

Involvement of adolescents

How services are designed

Yes = 7

Denmark, Germany, Netherlands, Norway, Serbia, Sweden, UK

No = 11

Austria, Belgium, Croatia, Czech Republic, France, Greece, S Ireland, Portugal, Slovenia, Switzerland, Turkey

How services are delivered

Yes = 10

Limited Czech Republic, Denmark, France, Netherlands, Norway, Portugal, Serbia, Sweden, Slovenia, UK

No = 8

Austria, Belgium, Croatia, Germany, Greece, S Ireland, Switzerland, Turkey

This however varies across the UK with some local authorities having health and wellbeing boards which involve young people in all aspects of service design from health, to social care and education (UK)

They are involved in their health care planning, for example, in therapeutic regimen planning and integration of healthy lifestyles (Portugal)

They are involved in the planning of their individual transition process. There is one structured programme ("Berliner Transitions programm") (Germany)

In some services adolescents are involved in planning how services are delivered (France)

This however depends on the chronic disease and also on the hospital (Netherlands)

Shared protocols

Yes = 6

Czech Republic, Denmark, Germany, Norway, Serbia, Sweden

There are some shared protocols between children's and adult health services for cancer treatment (Norway)

No = 12

Austria, Belgium, Croatia, France, Greece, S Ireland, Netherlands, Portugal, Slovenia, Turkey, Switzerland, UK

Except in rare cases of chronic diseases where both children and adolescents are treated in the same centre. For example, thalassemia, congenital heart diseases, cystic fibrosis and chronic psychiatric disorders (Greece)

Even if some protocols are almost the same, no sharing is organised between those two sectors (France)

There is a national clinical director for transition showing the commitment in the UK to this important area of practice and a great deal of work has gone on in many centres to improve services for young people (UK)

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