



# **National Steering Group for Specialist Children's Services**

## **Report of the Age Appropriate Care Working Group**

## **Table of Contents**

Executive Summary.....	1
Introduction.....	3
Background.....	5
Current Situation in Scotland.....	7
The Way Forward.....	10
Philosophy of Care.....	10
Training.....	11
Facilities, Accommodation and Models of Care.....	14
Staffing.....	21
Education.....	24
Transition.....	26
Workforce.....	28
Resources.....	29
Conclusion.....	34
Bibliography.....	35
Appendix A:	
Remit and Membership of Working Group.....	36

## **Executive Summary**

- Young people make up 10% of the Scottish population and are responsible for around 4% of hospital admissions (48,000 per annum)
- The specific developmental, emotional and psycho-social needs of adolescent patients are well recognised but have traditionally been poorly addressed by the hospital services and facilities provided in the UK
- The recommendation, initially made in Building A Health Service Fit For The Future, to raise the age limit for children's services in Scotland to the 16<sup>th</sup> birthday needs to be accompanied by specific planning and investment to ensure that young people receive age appropriate care
- In parallel with the development of services within children's hospitals there is a need for a full engagement with adult hospital services which will remain the principal provider of care for young people aged 16 and over
- No single model of service or facilities will be applicable across the range of hospital settings in Scotland. There is however need for all hospitals to actively explore innovative solutions, informed by key principles, that give priority not only to the clinical care of adolescent patients but also their developmental, psycho-social and educational needs
- Staff caring for young people should receive training to equip them to identify and address the particular and distinct needs of this age group
- Services should be organised so as to minimise educational loss as a result of hospital care, particularly for young people with chronic conditions
- The transition of patients from children's to adult services is a key element of successful care which needs to be well planned and structured
- Service provision needs to be responsive to the emerging autonomy and independence of adolescent patients and to encourage them to take responsibility for their own health care

## **Key Recommendations**

The following is a summary of the principal recommendations contained in the report

### Training

- Health Boards should identify any specific clinical training requirements arising from the change in age limits and ensure these are addressed

- NHS Education in Scotland should undertake a Training Needs Analysis of the requirement for generic skills training in adolescent care
- By 2012 all staff working with young people should have received appropriate generic training

### Facilities

- Health Boards should review the volume and pattern of adolescent admissions and identify opportunities for the provision of dedicated hospital facilities
- Where a formal adolescent unit or facility is not viable, Health Boards should ensure alternative means of delivering age appropriate care are provided

### Staffing

- Hospitals caring for adolescents should develop sustainable models for providing the range of competencies required to support age appropriate care
- Clinical leads for adolescent services should be identified at hospital and regional level

### Education

- All hospitals admitting young people should have strong and effective working relationships with educational providers and clear arrangements to ensure timely referral

### Transition

- A working group should be established to scope the extent to which the existing range of adult services fails to address the needs of young people with specific chronic or complex clinical conditions
- The recommendations of the Transition Working Group of the Royal College of Physicians of Edinburgh should be adopted and progressed

### Workforce

- Health Board and Regional workforce plans should specifically recognise the skill mix required to address the psycho-social and developmental needs of adolescent patient

### Symposium

- A national symposium on hospital care for adolescents should be held in 2008

## Introduction

*Adolescence .. is the 'increasing' of life*

*Dante*

In the National Framework for Service Change in the NHS in Scotland, “*Building a Health Service Fit for the Future*” (2005)<sup>1</sup>, there was a recognition of the need to ensure that facilities, services and models of care for young people were developed and provided in ways that recognise the particular needs of this age group.

With specific regard to hospital admissions Scotland has historically been at variance with England, North America, Australia and many parts of Europe in setting relatively low upper age limits for its children’s hospital services. As a result many patients aged 13 years and over have routinely been admitted to adult units within which the ethos and emphasis is inevitably orientated towards a much older patient population.

By way of response one of the recommendations of Building a Health Service Fit for the Future was that “*NHS Scotland adopts the guiding principle that the age for admitting children and young people to acute care in paediatric facilities is up to their 16<sup>th</sup> birthday dependent on their clinical need and patient choice*”. In recognition of the need for flexibility in the use of age limits in order to accommodate differing circumstances and preferences it was also recommended that “*for young people between the ages of 16 and 18 there should be discussions with their clinician(s) regarding where care is best delivered, recognising their right of choice, unless there are clear clinical reasons which determine whether admission is to paediatric or adult facilities*”.

The aspiration to extend the role of children’s hospital facilities to at least include most or all patients up to 16 was subsequently reflected in the Action Framework for Children and Young People’s Health in Scotland “*Delivering a Healthy Future*” (2007)<sup>2</sup> which charged the Children and Young People’s Health Support Group (CYPHSG), of which the National Steering Group is a sub-committee, with undertaking “*a scoping exercise... to determine the clinical, training and practical implications of implementing the recommendation that children up to their 16<sup>th</sup> birthday are admitted to age appropriate facilities*”.

The Age Appropriate Care Working Group (AACWG) of the National Steering Group was specifically tasked with progressing this work and bringing forward proposals for inclusion in the National Delivery Plan for Specialist Children’s Services.

The remit and membership of the AACWG is detailed in Appendix A. Although the remit was influenced by the particular implications and opportunities inherent in raising the age limit for children’s hospital services, many of the recommendations emerging from the work of the group are equally and explicitly valid for adult services which will continue to provide services for young people aged 16 and over.

The working group, which benefited from a membership drawn from a wide range of disciplines, organisations and geographical areas, met on six occasions between September 2006 and August 2007. In addition the work of the group was supplemented by -

- A survey of existing hospital service provision (including examples of good practice) undertaken in collaboration with the Health Board Child Health Commissioners
- Collaboration with Information Services Division and other services regarding activity patterns and service utilisation
- A review of key publications and guidance relating to adolescent care
- Direct consultation with representative groups of young people

Although Child and Adolescent Mental Health (CAMH) and Obstetric services were represented on the AACWG the report itself has not focused directly on these areas. CAMH services have been in the vanguard of providing dedicated adolescent care for many years and maternity units will not be directly affected by the change in age limits. It is also true that the report does not seek to address itself to adolescent care in Primary Care or community settings. However many of the issues raised, principles expressed and approaches recommended in the report will have relevance to all of these aspects of healthcare.

In the development of its remit the working group specifically recognised that whatever improvements are made for the care of young people within the children's hospital services there will still be a requirement to ensure that the transition to adult services of young people with long-term conditions is recognised in its own right as a vital element of the patient journey. In that regard the AACWG has formally aligned its review with parallel work being undertaken by a Working Group chaired by Professor Chris Kelnar under the auspices of the Royal College of Physicians Edinburgh which is specifically considering issues relating to transition and the transfer of care.

### *Terminology*

Adolescence is a developmental stage in life rather than simply a chronological period. Its commencement and completion are not precisely defined either in general, or in any one individual, and many aspects of maturation into adulthood may continue beyond the teenage years.

*Bridging the Gaps*, the report of the Intercollegiate Working Party on Adolescent Health (2003)<sup>3</sup>, elected to focus primarily on young people aged 13-18, an age range corresponding to the time frame of secondary education which is one of the culturally defining characteristics of the adolescent period. This report has adopted a broadly comparable approach while recognising the need for flexibility of service provision in response to local situations as well as individual maturity and choice. Throughout the report the terms "young people" and "adolescents" are used in an interchangeable way as appropriate.

## Background

*'Adolescents have distinctive and different needs from both child and adult patients'  
At Home in Hospital, Scottish Office (1993)*

Adolescence is a period of significant, and sometimes rapid, change and development – physical, emotional, sexual, social and behavioural. These changes are normal and healthy and mark the natural transition of the child into the mature adult.

Conversely however the selfsame issues can materially and adversely affect the ways in which young people view their own health and safety; respond to and cope with illness and interact with and use health services. This, in turn, may be reflected in patterns of risk taking behaviour and its consequences (substance abuse, trauma, sexually transmitted infections); non-compliance with treatment; poor engagement with health care and health care workers and the significant psycho-social complications that often accompany any chronic illness during this period.

Although there are few clinical conditions uniquely associated with the adolescent years there are many that may manifest themselves, or be substantially aggravated, as a result of this period of physical, sexual and mental development.

It is further true that the health behaviours established in adolescence are likely to persist into adult life. This represents both a significant concern but also a real opportunity since the encouragement of healthy lifestyles during this stage of life has the potential to generate long-term benefit.

Adolescence is also a period of emerging autonomy. The parent child relationship of earlier years is subject to changes that both parties may find difficult to embrace, particularly in the context of chronic or serious illness. The young person's increasing capacity to be responsible for their own health and legally competent to make their own decisions requires discernment and judgement on the part of parents and staff. These and other allied issues are more fully addressed in *0-18 years: Guidance for all doctors* recently released by the General Medical Council (September 2007)<sup>4</sup>.

For all these reasons, the last 50 years have seen an increasing recognition of the need for the planning and provision of health services, and the training and competence of the staff who deliver them, to take appropriate cognisance of the specific needs of adolescent patients<sup>3,5-9</sup>. This requirement straddles all aspects of health care, much of which will be community-based, but includes the particular need to provide hospital-based facilities and services appropriate to this age group.

In practice progress has been slow and incomplete. Significant emphasis has been placed on the development of adolescent services in some countries including Australia and the Scandinavian countries but this has not been reflected in the UK. A survey of adolescent service provision in the UK, undertaken in 2002 by the Royal College of Nursing,

identified only 13 dedicated adolescent wards and 5 adolescent oncology units<sup>10</sup>. None of these were in Scotland.

In 2004 the Health Care Commission *Patient Survey Report – Young Patients*<sup>11</sup> found that, across England, around 20% of hospital patients aged 12-18 had been accommodated in adolescent facilities. Of those young patients who would have indicated a preference to be in some form of adolescent ward 58% were accommodated in a children's ward and 16% in an adult ward.

A recent review of the Young Patient Survey<sup>12</sup> compared the experience of young people cared for in an adolescent ward with those nursed either in children's or adult facilities. Those 15-17 year olds nursed in an adult ward reported significantly poorer experiences across a range of issues relating to confidentiality; feeling secure; being treated with respect; having confidence in staff; being involved in their care and the availability of leisure facilities. Younger adolescents (aged 12-14 years) accommodated in a children's ward were also less likely to report excellent care with particular comment being made regarding the inability to have proper involvement in their own care.

These general observations were clearly reiterated in the consultation with young people undertaken as part of this work.

*'..without any information I'd think "I'm grown up, I'll go to an adult ward!" but if I was told I'd be in a room with the youngest person being more than 30 years older than me, and that there was nothing to do, then I'd choose a children's ward...even if that meant putting up with toddlers'*

*'..being thrown into the big hospital routine is frightening. Being woken early for things like blood samples (6.30am!), or because the lights go on isn't normal. I was told it was because 'that's the way it's done'. It also makes the day hard when my sleep has been disturbed due to children crying or bleeps of machines.. then you are told to get up and not be lazy'*



## **Current Situation in Scotland**

### *Hospital activity*

Of the 1.2 million hospital admissions annually in Scotland (inpatients and day cases) around 4% (48,000) are for patients aged from 12-19 (Table 1)

<b>Age</b>	<b>Emergency</b>	<b>Elective</b>	<b>Transfer</b>	<b>Day Case</b>	<b>Total</b>
12-15 yrs.	10827	3489	1055	5911	21282
16-19 yrs.	13848	3832	1644	7688	27012

**Table 1 – Average annual admissions by age and admission category  
(excluding obstetric and adolescent psychiatry admissions)  
[ Information Statistics Division – based on data for the years 2003-2005]**

Inevitably these admissions are spread across the full range of medical and surgical specialities. A significant percentage of admissions falls in the categories of general medicine and medical paediatrics (23.2%) and general or paediatric surgery (17.2%). Other specialities that have relatively high levels of hospital activity in adolescents include orthopaedics (11.2 %), ENT surgery (9%), haemato-oncology (4.5 %), oral surgery (3.8 %), plastic surgery and gynaecology.

The precise distribution of the patients between children's in-patient units and adult wards is not readily extractable. Widespread practice suggests that the substantial majority of patients aged 16 or over will be admitted to adult wards although a few with specific clinical needs or learning disabilities remain under the care of children's services. Around 30% of patients aged 12-15 years are admitted to one of the three separate children's hospitals in Aberdeen, Edinburgh and Glasgow. A further significant cohort in this age group will be admitted to the children's units in Ninewells Hospital or local District General Hospitals around the country. Practice in this regard will vary depending on existing age limits (see below).

Equally however many young people in the age range 13-15 years, particularly those requiring secondary care for non-specialist conditions, are still cared for in adult units. This is particularly true in Edinburgh and Glasgow where the age limit of the 13<sup>th</sup> birthday is consistently applied for new admissions unless there is a specific specialist requirement for care at the designated children's hospital.

In addition to the above in-patient activity there are over 95,000 new out-patient appointments (including obstetrics and psychiatry) for patients aged 12-19 each year (12-15 years 44,350; 16-19 51,050).

National data for accident and emergency attendances by age is not available however evidence from a recent review of accident and emergency activity within Glasgow demonstrates that of a total of over 300,000 attendances during 2006, 3.1% involved patients aged 13-15years.

### *Current Hospital Admission Policies*

Across Scotland the substantial majority of children aged 12 and under, and young people aged 16 and over are respectively admitted to children's or adult facilities. Policy and practice in the age group 13-15 years is inconsistent with considerable variation between regions, hospitals and individual speciality services throughout the country.

A survey conducted by the AACWG showed that the upper age limit of the larger dedicated children's units and hospitals varied from 13<sup>th</sup> to 16<sup>th</sup> birthday (Table 2).

<b>Current routine age limit for Children's units / hospitals</b>	<b>Hospital</b>	<b>Total</b>
Up to 16 <sup>th</sup> Birthday	Wishaw General Hospital Dumfries Royal Infirmary St John's Hospital Crosshouse Hospital Borders General Hospital Dr Gray's Hospital, Elgin Raigmore Hospital	7
Up to 15 <sup>th</sup> Birthday	Royal Alexandra Hospital, Paisley	1
Up to 14 <sup>th</sup> Birthday	Royal Victoria Infirmary, Kirkcaldy Queen Margaret's Hospital, Dunfermline Stirling Royal Infirmary Royal Aberdeen Children's Hospital Tayside Children's Hospital (Ninewells)	5
Up to 13 <sup>th</sup> Birthday	Royal Hosp. for Sick Children, Edinburgh Royal Hosp. for Sick Children, Glasgow	2

**Table 2 – List of individual hospitals and current upper age limits**

This situation is evolving. The Royal Aberdeen Children's Hospital anticipates raising the age limit to 16<sup>th</sup> birthday by 2008. In Edinburgh and Glasgow plans to move the age limit for their children's services to the 16<sup>th</sup> birthday will be progressed in conjunction with the development of their new children's hospitals currently scheduled to open around 2011 - 2012

### *Dedicated Adolescent Facilities*

There are currently no formally constituted adolescent units in Scotland. A 6 bedded unit sponsored by the Teenage Cancer Trust was recently opened (2007) in the Beatson

Oncology Centre, Glasgow, albeit the age limit for this unit straddles from late teen to young adults up to around 24 years of age.

A survey conducted by Action for Sick Children (Scotland) in 2000<sup>13</sup> suggested that 44% of all the wards admitting patients aged 0-18 offered “special facilities” for adolescents although these may take the form of equipment (eg computers etc), day room space etc as opposed to in-patient accommodation.

In practice many units do seek to make some specific provision for adolescent patients through the allocation of single cubicles or, in some larger District General Hospitals, a small bed bay

*In Borders General Hospital the Paediatric Ward has a designated three-bed bay designated for adolescent patients as well as cubicles that offer increased flexibility. Young people themselves are offered a degree of choice regarding the most appropriate admission option unless there are over-riding clinical issues*

There is also a range of examples across Scotland of good practice in regard to the development of services or posts specifically focused on the needs of adolescent patients

*The Royal Hospital for Sick Children, Glasgow, has a Youth team – Nurse Specialist, Youth Worker (part-time) and Activities Coordinator (part-time) – working in collaboration with link nurses in each ward. In addition to working directly with adolescent patients the Team raise awareness of adolescent care issues and ensure young people are involved in service design and evaluation.*

# **The Way Forward – Implementing the Age Limit Change and Developing Age Appropriate Services**

## **1. Philosophy of Care**

As already described in this report adolescence represents a distinct, if not rigidly defined, developmental stage, the characteristics and consequences of which need to be reflected in the health care provided to young people including, in particular, those accessing hospital services.

In practice the range of circumstances and scenarios within which hospital care will be provided to young people will vary enormously across the spread of geographic locations and hospital services represented in Scotland such that no single pattern of services, facilities or accommodation will be appropriate or deliverable. It is however true that there are key principles that should underpin whichever service models are developed and provided. These principles are not necessarily unique to young people but they do require to be specifically interpreted for the needs of this age group. Equally they add to, and do not replace, the core principles that inform all patient care.

**Although expressed in the context of a report specifically focusing on hospital services these principles reflect issues that are largely pertinent to the provision of health care to young people whatever the setting.**

### *Key Principles*

**Staff:** All staff with a significant or primary role in providing health care to adolescents should have specific training, to an appropriate level, in the distinctive physical, psychological, social and behavioural aspects of adolescence including the implications of emerging autonomy.

**Accommodation and Facilities:** The accommodation and facilities provided for young people should be designed not only to cater for their direct clinical care but also to support educational, social and recreational activities that meet their wider needs.

**Education:** Education is a vital element in the life of all children including, very particularly, those of secondary school age. Health care provision should be explicitly structured so as to minimise the adverse impact of illness on a young person's educational progress and to support continuing education wherever possible.

**Health Improvement:** The attitudes adopted in adolescence often persist into adult life. In addition to providing treatment for illness, services for young people should be structured so as to actively encourage health behaviours and lifestyle choices in ways that are appropriate for this age group.

**Respect:** All patients should be treated with respect. In the case of young people this needs to be particularly reflected in a pattern of service delivery that acknowledges -

- their increasing capacity to be active participants in decisions relating to their care
- their increasing responsibility for their own health
- the importance they attach to confidentiality
- their need, as appropriate, for the support of both family and friends

**Choice:** Influenced by issues to do with their maturity, clinical condition, past experiences and other determinants of personal preference, young people will have their own views on the best setting for their clinical care. Where clinical and allied matters permit, and more than one care setting is realistically available, there should be opportunity for the young person to exercise choice regarding the facility to which they are admitted or the service which they access.

**Involvement:** In addition to their proper involvement in decision-making regarding their own health and care, young people should be actively involved in the planning and design of the facilities and services intended for their use, both in hospital and community settings.

*You're Welcome – making health services young people friendly* (Dept. of Health, 2007)<sup>14</sup> and the *European Association for Children in Hospital Charter and Annotations* (2002)<sup>15</sup> offer further guidance on quality criteria that reflect best practice in both community and hospital services for adolescents.

## **2. Training**

The proposed change in the upper age limit for children's hospital, and the accompanying focus on adolescent care, raises two separate issues in respect of staff training -

- (i) Clinical
- (ii) Generic

### *Clinical Training Needs*

The need for speciality, condition or procedure specific clinical training as a direct consequence of the proposed shift in age limits will vary markedly between hospital services within Scotland. In many DGHs the change will have little or no impact on the case mix of individual clinicians and consequently no implications for new or refresher training.

By contrast the raised age limit will have its most explicit effects in the major cities, and in Edinburgh and Glasgow in particular, where secondary care for young people aged 13-15, which is currently delivered in the adult sector, will transfer to the children's hospital in the future.

In practice many of the clinical scenarios seen in this age group will also be present in younger children and therefore will not present any specific training challenge. There are

however a number of areas in which some staff groups may be presented, or presented much more frequently, with clinical problems rarely seen in their present practice.

Specific examples include -

- Gynaecological conditions presenting as medical or surgical referrals
- Differing patterns of orthopaedic trauma reflecting both a different range of activities and stage of skeletal development
- Different manifestations of abuse, particularly emotional and sexual, from those seen in younger children
- Presentations due to self-harm or drug or alcohol abuse
- Conditions directly related to puberty and growth

In addition to changes in the pattern of clinical problems it also needs to be recognised that the change in age limits will present children's services, particularly dedicated paediatric A&E units, with a cohort of young people whose behaviour, often as a result of alcohol or substance abuse, poses problems for staff and other patients which are rarely seen in younger children.

The extent to which these and other comparable issues do, or do not, bring accompanying training issues will largely depend on the existing service configuration and the practice and previous training of individuals across the clinical disciplines. Many clinicians working with children have clinical practices that already include young people and adults and many others will have come through training programmes which incorporated adolescent and adult experience.

In reviewing this issue the AACWG could discern no major specific or widespread training issue within any of the clinical disciplines that would require a nationally led programme of additional clinical training. There will however be a need for individual hospitals and specialities to ascertain whether any individuals, or groups of clinicians, have specific training needs relating to any change in their practice that may result from a change in the age limits. This will be particularly important in the context of the preparatory work undertaken in Edinburgh and Glasgow in anticipation of the opening of the new children's hospitals.

Advice received by the group suggested that where individual clinicians perceived the need for additional training this should be accessible from within the existing courses and training opportunities already accessible by staff (either within the NHS in Scotland or through other training providers) without the need for any new or different provisions.

***It is also important to note that once the new children's hospitals in Edinburgh and Glasgow have become operational, all children's hospital services in Scotland will be co-located with adult services. This physical juxtaposition should be accompanied by a strong emphasis on collaborative working between children's and adult services in the provision of adolescent care. There should be sufficient flexibility of practice to ensure that the respective skills and experience of both adult and paediatric clinicians, across the disciplines, can be engaged in the care of individual young people irrespective of the clinical area to which they are admitted.***

**Adolescent Units:** A key emphasis within this report is the development of dedicated adolescent units or areas within hospitals. Such units will, by definition, admit patients from across a range of medical and surgical specialities. As a result the nursing skill mix within any adolescent unit needs to incorporate an appropriate range of competencies. Experience from other units elsewhere in the UK and abroad suggests that this can be successfully achieved.

Such an approach may, in part, be addressed by having a nursing team drawn from different speciality backgrounds and, where appropriate, from both adult and paediatric sectors. It will however also require individuals to enhance their competency base and will therefore raise specific training needs which will require to be identified and addressed in ways that are tailored to specific local requirements.

**Recommendation:**

In implementing the change in age limit for children's hospital services Health Boards should ensure that

- a multi-disciplinary scoping exercise is undertaken to identify any specific clinical training needs arising as a result of the change in the case mix within children's services and
- appropriate arrangements are put in place to provide the required training

*Generic*

The specific and different attributes of adolescence need to be adequately understood and appropriately addressed by all staff, whether hospital or community based, who have any substantive responsibilities for delivering care to this patient group.

This requirement incorporates issues as diverse as -

- Communication skills
- The capacity to interpret and respond to emotional and behavioural issues
- The legal framework relating to consent and associated matters
- Awareness of the developmental changes associated with adolescence
- The ability to handle evolving parent/child relationships

A number of professional training programmes already include elements and competencies relating to the care of adolescence including the Royal College of Paediatrics and Child Health (RCPCH) core competencies for paediatric medicine and the curriculum for children's nursing.

Other clinical disciplines do not routinely incorporate adolescent training in their curricula and equally there may be staff who have previously received training in adolescent care which has not been utilised in the more recent past.

If we are to ensure high quality age appropriate adolescent care throughout Scotland there is an initial need to -

- Ascertain the potential number of staff whose on-going roles involve adolescent care and who lack relevant training
- Determine the core competencies which staff involved in adolescent care can realistically be expected to either have or acquire
- Identify any existing training programmes or material which could be accessed in order to address generic staff training needs

Following discussion with NHS Education Scotland (NES) agreement has been reached that a preliminary Training Needs Analysis will be undertaken to address the above issues. In that regard it is noted that an on-line training package is currently being developed by the RCPCH, in collaboration with other professional bodies and education providers, which is designed for use by various clinical disciplines and which should be available during the course of 2008.

**Recommendation:**

A Training Needs Analysis is undertaken by NES during 2008 to scope the requirement for generic training amongst clinical staff providing adolescent care in Scotland and to identify the training options available.

**Recommendation:**

By 2012 all staff working with young people will have received appropriate generic training in the care of adolescent patients.

### **3. Facilities, Accommodation and Models of Care**

Given that adolescence straddles both the traditional and incoming age limits for children's and adults services it will remain true in the future that young people will receive hospital care in a number of different settings -

- A specialist children's hospital
  - most 13-15 year olds
  - some aged 16 years and over for specific reasons relating to clinical condition or patient choice(as already noted, in the future all the specialist children's hospitals will be directly co-located with adult hospitals)
- A children's unit within a General Hospital
  - most 13-15 year olds
  - some aged 16 and over (as above)



- A unit or hospital primarily accessed by adult patients
  - some 13-15 year olds (for example in community hospitals, district general hospitals with no paediatric unit)
  - most patients aged 16 and over
- Maternity and adolescent psychiatry units
  - all adolescent patients requiring these specific facilities

The accommodation and facilities provided, and the models of care adopted for adolescents will clearly be influenced by the specific local service configuration and also issues relating to case mix and activity levels. As such no single pattern of adolescent service will fit every hospital setting however the principles and proposals described below, although most easily addressed by the creation of a formally designated adolescent unit, can be used to inform any and all settings into which young people are admitted.

### *Inpatient Accommodation*

In 1993 the Scottish Office Home and Health Department<sup>8</sup> advised Health Boards that good practice in the hospital care of adolescents required

- the accommodation of adolescent patients in a separate unit from children's and adult wards which can provide privacy, flexibility of regime and independence
- space for socialising, hobbies, homework or just to be alone

Existing guidance contained in reports such as Youth Matters (1998)<sup>9</sup> and Bridging the Gaps (2003)<sup>3</sup> sets out the key principles which should inform the development of any adolescent inpatient facilities and the issues that require to be addressed. Inevitably many of the features required are common to all in-patient areas within a hospital (interview rooms for counselling and confidential discussion, disabled access, toilet facilities that offer appropriate privacy etc) but specific and additional issues include -

**Gender Mix:** Socialisation, including socialisation between the sexes, is a key element of adolescence and adolescent facilities should foster such opportunities. Individual bed bays necessarily require to be single gender in order to respect the privacy that is seen as a very important requirement amongst young people. However, wherever local arrangements permit, the overall cluster of accommodation provided for adolescents should permit both male and female occupancy.

**Single Rooms:** Largely driven by concerns about infection control there is an increasing move towards all in-patient hospital accommodation being provided in single rooms. This runs counter to existing guidance regarding adolescent inpatient facilities and the declared preferences of the young people consulted for this report who favour a mix of accommodation which includes shared occupancy areas (either 2 or 4 bed rooms) as well as single rooms. In addressing the important role that socialisation plays in the lives of most young people the interaction supported by shared accommodation may also help

prevent the pattern of depression and social withdrawal that can sometimes accompany periods of ill health and be aggravated by periods of isolation.

**Recreational and Social Facilities:** A recurring finding in surveys of young people in hospital is a complaint of the lack of appropriate facilities for recreation and peer-group interaction. Such provision is a necessary part of addressing the psychological and social needs of adolescent patients. Any such facilities require to be equipped with appropriate leisure equipment, computers, snack dispensers (healthy options) etc.

In parallel with the need for recreational and social space there is also a need for some protected quieter area that young people can use when they need time to themselves.

Adolescents' attitude to food, both what is eaten and when it is wanted, are a particular manifestation of this period of physical and personal development. Rigid hospital routines and traditional menus (particularly those often provided in children's ward) run very counter to their normal life and significantly increase the sense of hospitalisation and loss of independence.

While recognising some of the constraints which relate to the provision and preparation of food in hospitals, access to appropriately managed self-catering facilities within adolescent facilities significantly enhances the normalisation of a young person's hospital experience and the likelihood of adequate dietary intake.

**Education:** Dedicated space to pursue their educational activities is a vital requirement for adolescent patients. The importance of minimising the potential educational loss due to illness is emphasised elsewhere in this report but a necessary aspect of educational provision is the availability of adequate space for teaching and personal work. Any such space requires to be appropriately equipped to support the required range of educational activities including, very particularly, the need for computers, appropriate software and internet access. Similar IT provision is required at the bedside for those young people unable to use the communal educational accommodation.

**Age Limits:** Although its boundaries are indistinct, adolescence is normally taken to at least span the period from 13-18 years of age, an age range that accords closely with secondary schooling which is a parallel life experience most adolescent patients will share.

The circumstances in which adolescent facilities are developed may determine, in large measure, the age range accommodated. For example adolescent facilities, or an adolescent unit, provided within an adult hospital would primarily serve patients aged 16 years and over and may even be extended into the young adult population in their early 20s (a number of the units supported by the Teenage Cancer Trust, including the one recently opened at the Beatson Oncology Centre in Glasgow, are targeted at such an age group). Equally, adolescent facilities provided within a children's unit or hospital will focus primarily on younger adolescents, principally under 16 years.

As identified elsewhere in this report, given that adolescence straddles traditional boundaries between children's and adult services, there is no fundamental reason why adolescent facilities cannot be structured so as to accommodate patients from both children's and adult sectors.

In such circumstances it is recognised that the developmental and cultural gap between the older and younger end of the potential age spectrum becomes increasingly significant. Young people themselves feel that an age range of around 13-18, which mirrors the period of secondary schooling, offers an entirely reasonable age mix for a dedicated facility albeit, depending on local circumstances and activity patterns, there could be opportunities to extend such age limits slightly in either direction.

**Complex Needs and Learning Disabilities:** Children with combined physical and learning disabilities represent a significant cohort of the population of young people admitted to hospital. In practice such patients often remain under the care of children's services significantly longer than other patient groups, partly because a children's service may better suit their needs and partly because of the paucity of corresponding and suitable adult services.

The coexistence of significant physical and learning disabilities may have a material impact on an individual's pattern of development and maturation and, consequently, on the configuration of facilities and services that best meet their needs. Given that the 'added value' of dedicated adolescent facilities largely relates to addressing the psychosocial and developmental needs of the young person (as opposed to their direct clinical care) the extent to which a teenage patient with complex needs and learning difficulties will be best cared for, and able to benefit from, such facilities will vary considerably from individual to individual.

It is not therefore realistic to offer any single or blanket recommendation regarding the role of dedicated adolescent facilities in the hospital care of such patients. Decisions will require to be made on an individual basis taking into account the nature and severity of the young person's disabilities and their capacity to be advantaged by care in such a facility as well as being informed by patient and family preferences. Age appropriate surroundings should, however, always be considered.

**Ward Routines:** Hospitals often operate daily routines that are largely driven by staffing arrangements and long-standing models of clinical care and are at considerable variance with life outwith hospital. This can be particularly noticeable in the case of adolescent patients making hospitalisation a very abnormal experience.

Careful consideration needs to be given to the development of routines within any adolescent facilities that normalise the hospital experience as much as possible. This includes issues such as times of waking and sleeping, the pattern of meal times and, within these broad frameworks, a degree of flexibility to accommodate individual need and preferences. This is not arguing for a *laissez faire* approach but for an appropriately structured routine. In practice most adolescents' daily out-of-hospital routine will centre

around the school day and this may offer a reasonable template to shape the rhythm of a ward day. This would include the opportunity for educational and allied activities during afternoons which represents a period of maximum boredom reported by young people in hospital.

Inevitably all these issues need to be considered alongside the requirement to ensure the provision of safe and consistent clinical care and the necessity of sustaining credible staffing arrangements.

It is also important that ward routines and disciplines take cognisance of the emerging autonomy and independence young people can, and should, have for all aspects of their life including their health and health care. Responsibility for self-medication and the ability to prepare and eat snacks outwith traditional meal times are very practical examples. How these matters are reflected in individual cases will be dependent on many factors but adolescent facilities and services should have the capacity both in terms of ward routines, staff training and attitudes and the physical facilities (for example bedside drug lockers, self-catering kitchen facilities) to support such an approach.

**Parents :** Although adolescence is characterised by increasing autonomy and independence most young people retain close and important relationships with their parents (or other primary carers). These relationships have particular importance during times of illness and hospitalisation.

Facilities provided for adolescents should support a high level of flexibility and choice in regard to the degree and pattern of parental involvement and presence during a young person's hospital stay. In addition to the option normally available in children's hospital facilities whereby a parent can stay overnight at the bedside there should, wherever possible, be accommodation which would allow a parent to remain elsewhere within the hospital since such arrangements offer a balance of accessibility and independence which many young people feel best meets their needs.

**Information Technology and Communication:** The impact of modern developments in information technology and communication have probably impacted on the personal lives of young people more than any other sector of the population. Their socialisation, education and entertainment are both shaped by, and dependent on, the options available to them through internet access, e-mails and mobile phones.

Any facilities developed for adolescent care need to ensure adequate and appropriate provision for internet access and e-mail communication. Ideally such a provision should be both in such common recreational space as is provided and also at bedside level.

Given the importance young people attach to the options provided by e-technology even hospital settings where patient numbers preclude the creation of larger adolescent areas or units can, through ensuring good access to appropriate e-facilities, offer adolescent patients a significantly enhanced pattern of in-patient care.

Inevitably internet access raises issues regarding the material and sites accessed. The provision of such access would therefore require to be accompanied by appropriate safeguards and disciplines, as already happens in schools.

The issue of mobile phones is complex although it is increasingly recognised that their direct risk, in terms of interference with medical equipment, is less than had previously been understood. Patterns of phone use can also be disruptive to other aspects of hospital routine, and even to the desired supportive socialisation amongst adolescent in-patients, albeit these issues are less impacted by text messaging which is frequently the most important element of phone communication. The fact that most mobile phones are equipped with cameras also raises potential problems in a hospital setting.

Local policies would be required regarding permitted locations for, and patterns of, mobile phone use but the availability of this option offers an important element of normalising hospital life.

### *Adolescent Units*

The most comprehensive way to address the issues identified above is through the creation of an adolescent unit. Inevitably the development of any substantive “unit” requires sufficient level of activity and there are two separate (and sometimes co-existent) drivers that tend to disperse adolescent activity and thereby mitigate against the development of adolescent units – speciality based services and the age boundary between children’s and adult services (even where this operates at or around the 16<sup>th</sup> birthday)

**Speciality Based Services:** The distribution of patients within a hospital is determined primarily by the nature of their illness and the clinical team directing their care. In most hospitals this leads to a broad division into ‘medical’ and ‘surgical’ services with further sub-divisions dependent on the specialty and activity pattern of the hospital in question. This reflects the need to ensure that care is led and provided by those with appropriate expertise and is also seen to offer organisational efficiency through clustering patients and the staff caring for them in a single area.

Such an arrangement does however focus largely on the patient’s clinical condition rather than their wider needs as an individual – an issue particularly relevant to young people who find themselves cared for alongside either very young children (around half the overall bed days for patients aged 0-15 are taken up by children in the first 5 years of life) or a largely elderly population.

Clearly clustering adolescent patients together may require a different approach to the delivery of specialist care but the evidence of existing adolescent units is that with appropriate training and skill mix for the core nursing staff, and flexibility in respect of other input to their care, a wide range of both medical and surgical care can be provided safely and effectively within such a unit.

Consultation with young people demonstrates a strong preference for their being accommodated with their own age group rather than within speciality-based areas. Even where an individual's condition requires isolation in a single room, for infection control or other reasons, the expressed preference remains to be "isolated" in a unit, the overall ambience and ethos of which is focused on the needs of adolescents.

**Age Boundaries:** The other factor that argues against investment in the creation of adolescent units is a belief that the level of in-patient activity is insufficient to justify such an approach. While this may be true in some smaller hospitals the perception regarding insufficient activity is undoubtedly increased by the fact that currently, and even with the introduction of the 16<sup>th</sup> birthday recommendation, the cohort of adolescent patients within many hospitals will be divided, with those aged 13-15 in children's services and those aged 16 and over dispersed in adult wards.

There is however no fundamental reason why an adolescent unit, appropriately staffed, cannot straddle the "traditional" paediatric adult split and offer an age appropriate care environment accessed by clinical teams from both the adult and paediatric services within a hospital. Existing evidence<sup>16</sup> suggests that a DGH serving a population of around 250,000 will have, on average, 18 in-patients aged 12-19 years at any one time.

In practice, hospitals in Scotland will serve a mixture of catchment areas, both larger and smaller, but an approach that recognises the totality of the adolescent patient population within a hospital as a single group with shared needs creates an environment in which different opportunities exist to provide age appropriate accommodation and services.

Such an approach requires a willingness to think innovatively, to collaborate across traditional clinical boundaries and, at times, to place patient's needs and preferences ahead of professional convenience. It is probably most applicable in a DGH setting but the opportunities inherent in the current and future co-location of Scotland's specialist children's hospitals alongside major adult facilities may also provide the opportunity not only to develop units for younger adolescents within the children's hospital but also to consider imaginative approaches across the paediatric adult boundary.

#### *Other Inpatient and Short-Stay Facilities*

In keeping with the wider trends in modern hospital practice many adolescents will be cared for in a variety of short stay or day care facilities. It is also recognised that there are valid reasons why the management of teenage pregnancy will most appropriately be conducted within obstetric services separate from other inpatient areas.

In these settings adolescent patient numbers may limit the extent to which dedicated facilities can be developed however the principles identified in this section remain valid and should be appropriately reflected in the facilities and services provided. The services and staff mix associated with in-patient adolescent facilities, where present on the same site, may also offer support to colocated ambulatory, day care and maternity services on an 'outreach' basis

### *Out-patient Facilities*

The volumes and patterns of attendance of young people at out-patient clinics will vary substantially between hospitals and also between specialities within the hospital. It is also true that many of the elements of accommodation provision in out-patient departments are reasonably generic across the spectrum from children through to adults.

The principles that are expressed elsewhere in this report both in terms of the overall approach of adolescent services and the provision of accommodation should be taken into consideration in terms of out-patient facilities which serve young people.

In practice the pattern of out-patient provision for young people may be as important as the accommodation itself. Depending on activity levels, and also other issues arising from the management of transition, consideration should be given to providing some clinics specifically for young people. In such circumstances the ethos and approach adopted can be better tailored to their increasing maturity and emerging independence and issues such as clinic timing can be organised to minimise educational disruption – a key issue for those with chronic conditions requiring frequent attendance.

**Recommendation:**

Within each Health Board area a review should be undertaken of the overall pattern and volume of adolescent admissions with a view to identifying the opportunities that exist to create one or more dedicated multi-speciality adolescent units or equivalent. Such a review should specifically include the possibility of creating adolescent areas that are accessed by both children's and adult services where this option makes the viability of such a unit more credible.

**Recommendation:**

Where activity patterns do not support the creation of dedicated adolescent units (or equivalent) Health Boards should develop an action plan to ensure that alternative means are identified to address the key elements of age appropriate in-patient care in all settings where young people are routinely admitted.

### **4. Staffing**

In keeping with the issues relating to the provision of facilities and accommodation, as documented in the previous section, the precise staffing model required and adopted in any particular hospital setting will depend on the pattern and volume of activity and service configurations. The following comments are shaped around the staffing support for a dedicated adolescent area or unit but the inherent principles and competencies can be interpreted flexibly in any setting where young people are admitted.

Common to any staffing model is the key requirement that all clinical staff, and other staff groups where appropriate, who are caring for adolescent patients should have a sound understanding of the specific issues common to this developmental stage and the implications these have for care delivery and professional approach.

## *Nursing*

Being defined by age rather than clinical speciality adolescent units are almost always multi-speciality in their case mix (possible exceptions include teenage cancer units). Concerns are often expressed regarding the feasibility of developing satisfactory speciality-specific skills within the nursing pool supporting such a unit however evidence from existing successful adolescent units confirms that, with appropriate attention to training and skill mix, an entirely appropriate range of competencies can be provided and sustained across a wide range of medical and surgical specialities.

There may be some highly specific skills that cannot be realistically replicated within the nursing pool of an adolescent unit but, in such areas, options may exist either to make such provision on an in-reach basis as required or for the patient to leave the ward to access such specialist care without necessarily preventing the young person enjoying the benefit of receiving their overall care in an age appropriate setting.

Where the provision of adolescent care is best achieved by creating a unit that crosses the normal boundaries between adult and children's services the nurse staffing of the unit will require to incorporate an appropriate mix of registered adult and children's nursing staff to ensure that nursing care accords with the relevant professional guidance.

Nursing care is clearly a major element of adolescent in-patient care and a key determinant of whether that care is indeed age-appropriate. Whatever pattern of accommodation, and therefore nursing model, the hospital adopts, all hospitals admitting young people should have a senior nurse who has a particular remit, supported by appropriate training, to advise and support the overall provision of nursing care to adolescent patients.

## *Medical Staff*

Most medical staff dealing with adolescents will do so in respect of their particular speciality service. As such the key requirement (as reflected in the "training" section of this report) will be to ensure, especially in the context of the enactment of the shift in admission age limits, that they have the appropriate speciality specific clinical skills relevant to treating adolescent patients.

The other key requirement for medical staff, particularly in the development and establishment of adolescent facilities, is the need to adapt to a different model of inpatient care which will cross traditional speciality boundaries and will itself require to flexibly accommodate the clinical and organisational requirements of multiple specialities.

The development of adolescent medicine as a specific sub-speciality is still very limited and few hospital settings in Scotland are likely to support such a model, at least in the immediate future. However, as has been proposed with nursing care, there will be merit within many hospitals in the formal identification of a consultant who has a particular interest in, and responsibility for, adolescent care and who can offer support and advice as required as well as providing clinical leadership in developing adolescent services.



In parallel with the above recommendations regarding the perceived benefit of identifying key nursing and medical personnel who will take an active interest in the overall provision for adolescent care in hospital, the Action Framework also includes a recommendation, at regional level, that “*Regional Planning Groups should designate at least one clinician with responsibility for adolescent hospital care*”. Such an appointment can offer support and advice across the range of hospital settings within a region into which adolescent patients are admitted but does not alter the need, particularly within larger hospitals, for on-site representatives of nursing and medical staff who have an interest in adolescent care. Indeed there is no reason why such individuals could not also fulfil a regional role.

### *Allied Health Professions*

For staff within most branches of the allied health professions the key requirements in terms of adolescent care will be the acquisition of generic skills and the need to ensure, particularly in regard to any significant change in activity patterns consequent upon the age limit change, that they are appropriately trained for such specific clinical issues as pertain to the care of young people. In some larger units there may be room, within some of the allied health professions, for individual members of staff to develop a particular focus on adolescent care as it pertains to their profession.

### *Clinical Psychology and Psychiatry*

One of the defining characteristics of adolescents is the range of psychological and emotional issues that accompany this particular developmental stage. These issues are frequently compounded and complicated by the presence of concurrent ill health, particularly chronic conditions. Equally there are a number of scenarios in which emotional or psychosocial issues constitute the primary clinical problem, for example self-harm and eating disorders.

The effective provision of care to adolescent patients needs both to take cognisance of these issues and also to incorporate psychological and, where necessary, psychiatric support as required.

Hospital services dealing with adolescents therefore require to be able to access appropriate input from clinical psychology and adolescent psychiatry staff. Any unit dealing with substantial numbers of adolescent patients will require such support on a regular basis and appropriate provision should be built into the staffing profile of the services.

### *Play Therapists, Play Specialists, Youth Workers and Social Workers*

Age appropriate play and recreational activities have the capacity to make a significant contribution both to aspects of clinical care and also to the enhancement of the psychosocial environment of an adolescent area.

Equally young people coping with health issues will often require advice, support and counselling in respect of their illness and its wider implications. This may include vocational issues, welfare rights, community support as well as matters relating to the patient's social circumstances and family settings. There is also a parallel need to take appropriate opportunities to promote good health and healthy behaviours.

The skills required to address these issues potentially involve a range of professional backgrounds including play therapists, hospital play specialists, trained youth workers and colleagues from social work as well as nursing staff. With appropriate training individuals from within these staff groups may also extend their competencies to offer more generic support which crosses some of the traditional professional boundaries.

The precise model adopted by any hospital will depend on the particular circumstances and opportunities that exist but it is very important that these issues are considered and addressed within the overall skill mix of support staff.

### *Chaplaincy*

In keeping with the many other developmental changes associated with adolescence, the spiritual needs of young people are materially different from those of adult patients or younger children. Chronic or serious illness during adolescence raises very real and challenging questions and there is a need to ensure that hospital chaplains called to deal with adolescent patients are appropriately equipped and trained to address these issues.

#### **Recommendation:**

Hospitals providing care for adolescents should develop sustainable models that deliver the range of competencies and skills required to address not only issues of direct clinical care but also the psychosocial, developmental and spiritual needs of young people.

#### **Recommendation:**

In addition to the identification of a clinician with a regional responsibility for adolescent care (see Action Framework) all hospitals admitting significant numbers of young people should designate a local clinical lead or leads (medical and nursing) for adolescent services

## **5. Education**

One of the responsibilities inherent in the provision of healthcare to children and young people is the need to work with the relevant authorities to minimise the impact of prolonged, recurrent or chronic illness on the individual's educational achievements.

This requirement is particularly pertinent in adolescent care where the loss of educational time may have an impact on a young person's ability to prepare for, or participate in,

examinations or other activities that may directly affect their school qualifications and future life opportunities.

The Standards in Scotland's Schools Act (2000), and subsequent guidance issued in December 2001<sup>17</sup> details the arrangements that should be put in place when a young person is receiving hospital care. Specifically the guidance indicates that teaching should *"normally begin after 5 working days following admission, provide the child's state of health makes this desirable"* but that *"if a child's in-patient stay is known, or reasonably thought, in advance of that period to be likely to extend to or beyond 5 day then teaching should proceed immediately"*. This latter guidance is of particular importance for young people who require recurrent admission.

The achievement of these objectives requires an effective collaboration between hospital staff and the relevant education services, both hospital and school based, including robust referral procedures. It is particularly important that staff in adult wards, where younger patients comprise a small element of the overall case load, have a clear understanding of their responsibilities in respect of ensuring the young person's educational needs are identified and addressed.

**Recommendation:**

All hospital wards admitting young people should have clear procedures in place to ensure, wherever clinically appropriate, prompt referral to the relevant education provider of any school age patients whose admission is anticipated to exceed five days.

The arrangements for the provision of education in hospital – both generally and at an individual level – require effective collaboration between the clinical services, hospital-based teaching staff (if available) and the young person's own school or educational authority. The exact nature of such arrangements, which require to be agreed at a local level, need to be able to accommodate different clinical situations depending on the young person's pattern of treatment, mobility etc but should be influenced by a number of key principles -

- Wherever possible, and particularly in larger units, dedicated and appropriate equipped educational accommodation should be available for use whenever clinical constraints permit.
- Opportunities to maintain contact with the young person's own school and fellow pupils should be identified and maximised. Increasing availability of internet connections within hospitals can and should be used to facilitate such contact.
- Wherever possible, educational provision should support a rhythm and discipline which has some comparability to the school day. There is often an undue and potentially conflicting focus on clinical and educational activities taking place during the morning leaving substantial slack time in the afternoon that is both wasted and viewed by young people in hospital as 'boring'.
- Although each young person in hospital has their individual educational and clinical requirements there is benefit, wherever possible, in their engagement in a collective approach to educational activities. This requires both collaboration between educational and clinical care providers within the hospital as well as

appropriate agreement amongst the relevant education authorities and schools, along with the hospital teaching team, regarding the approach to be adopted

**Recommendation:**

Hospital services admitting adolescents should have in place clear arrangements with the hospital teaching team and all relevant education authorities which facilitate and maximise the educational provision both at an individual and collective level.

## **6. Transition**

*‘a purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents ..with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.’*

*National Service Framework, Dept. of Health (2006)*

At some stage in the trajectory of their care young people with long-term conditions will require to transfer to adult-orientated services. This move normally takes place in the context of the individual’s overall progression towards maturity and adulthood and in parallel with the wider changes that characterise adolescence. As a result it has increasingly been recognised and proven that the successful transfer of care should be handled in a well planned and coordinated transition process with which the young person and their family is fully engaged, and not by means of an abrupt referral to another clinical service.

*“I’d been going to the same clinic in the children’s hospital for years then one day I got a letter through the post giving me an appointment in another hospital – and that was it.”*

In recognition of the importance of this issue the Royal College of Physicians Edinburgh (RCPEd) established a working group under the chairmanship of Professor Chris Kelnar to develop guidance regarding the management of transition. Their work has focused on both the generic issues pertinent to all long-term conditions and the specific issues arising in the context of some of the commoner chronic illnesses affecting adolescents.

In order to avoid inappropriate and unnecessary duplication of effort the AACWG reached early agreement with the RCPEd and the Transition Steering Group that the two working groups would liaise closely together on the understanding that the Transition Steering Group would, de facto, take forward the issue of transition care on behalf of the AACWG and develop the necessary guidance and recommendations. The output of that work will be published separately however, in the context of the National Delivery Plan for Specialist Children’s Services, it should be seen as complementary to this report on Age Appropriate Care.

**Recommendation –** Informed by the guidance and recommendations of the Transition Steering Group, Health Boards should ensure that all their care pathways for young people with long-term conditions incorporate well structured arrangements which support effective transition from children’s to adult services.

One specific issue within the overall transition arrangements for any patient is the age at which the care of a young person formally transfers to the corresponding adult service. Current practice, influenced by the traditionally low upper age limit applied to children's hospital services, tends to result in patients being transferred in their 'mid-teens'. This pattern however places the changes and challenges inherent in the transfer to another care provider right in the heart of the patient's other key, and often challenging, transition process – the developmental journey from child to adult.

Evidence gathered by the Transition Working Group suggests that patient preference favours care remaining with the paediatric service provider through the principal stages of adolescence with the formal transfer to adult services taking place at, or even beyond, 18 years of age. The adjusted age limits for children's hospital services, and the accompanying flexibility regarding 16-18 year old patients, provides a new opportunity to support a later age of transfer of care and to thereby offer a consistency of care provider throughout the main period of adolescent development.

Inevitably there will need to be sufficient flexibility to accommodate issues of individual maturity, patient choice and, in some cases, specific local service issues. However the opportunity provided by the age limit changes should be used as a basis for ensuring that the transfer of care does not occur when the issues generated by a change of service will further complicate the challenges associated with managing a young person with a chronic condition, and their family, through their personal adolescent development. Such an arrangement also aligns changes in health care provision more closely with other key markers of the transition to adult life, particularly in the arena of education and employment.

**Recommendation:**

While retaining flexibility to accommodate individual preference, maturity and, in some instances, local service provision considerations, the transfer to adult services of the care of young people with long-term conditions should normally take place at, or around, 18 years of age.

Effective transition is inevitably dependent on the existence of an adult service, appropriately configured to meet the needs of the young person, to which transfer of care can take place. There are however a number of clinical situations in which the absence of corresponding adult services raises substantial difficulties in ensuring the seamless progression of care.

In particular, medical advances are increasingly supporting the survival into adulthood of children and young people with life limiting conditions. The fact that such conditions were previously minimally reflected in adult practice creates a service gap which can only be addressed either by the paediatric team retaining clinical responsibility into adulthood or by transfer and transition into an adult service with little or no expertise in the condition in question. Neither of these scenarios, particularly where they happen by default in the absence of any viable alternatives, can be deemed satisfactory either from the perspective of the patient or in terms of clinical governance or good practice.

Similarly young people with complex needs and their families, particularly where there are co-existing learning difficulties, face a pattern of adult health care which is constructed entirely differently from that provided during childhood. In particular the absence of an identified clinical team taking overall responsibility for the young person's care and the consequent need to engage with a range of speciality specific services mitigates heavily against the achievement of successful transition and leaves patients and families feeling vulnerable and even neglected. As a consequence there is frequently strong pressure for young people with complex needs to be retained within paediatric services well into their adult years.

The continued existence of these issues is testimony to the fact that they do not offer easy solutions. The short-life nature of the AACWG has not permitted this matter to be considered in detail but the requirement to scope the extent of the problem and identify potential solutions is real and pressing.

**Recommendation:**

The SGHD, in collaboration with Royal Colleges in Scotland should establish a working group to scope the extent to which existing adult services fail to address the long-term needs of young people progressing to adulthood with complex needs or specific long-term conditions and to bring forward recommendations as to how these needs can be met.

## **7. Workforce**

Although this report is focused on the care of patients already within the health care system the implementation of the age limit change and the provision of high quality age appropriate care will impact on the NHS workforce in terms of both staff numbers and competencies.

### *Age Limit Change*

As has already been recognised, adjusting the upper age limit for children's services to the 16<sup>th</sup> birthday will impact differently across the spread of Scottish hospitals given the variable current criteria in operation regarding the admissions arrangements for adolescent patients, particularly those aged 13-15 years.

Where significant numbers of younger adolescents are still cared for in the adult sector, a situation that particularly applies in Edinburgh and Glasgow, the implementation of a revised age limit will result in a significant increase in the workload of the children's hospitals across the spectrum of their in-patient and out-patient services.

Although this represents a shift in workload as opposed to new activity, the capacity for individual staff (or overall resources) to follow the patients is likely to be extremely limited for both operational and professional reasons. NHS Lothian and NHS Greater Glasgow and Clyde, along with all other Health Boards in which the implementation of the new age limit will result in a significant movement of activity between the adult and paediatric sector, will require to undertake a scoping exercise to assess the impact on workload and the consequent staffing requirements in terms of numbers and skill mix.

In that regard it is clearly relevant that the incorporation of all 13-15 year old patients into the workload of the children's hospitals in Edinburgh and Glasgow is not currently scheduled to take place until the planned new hospitals are open. The planning process of these hospitals will not only include the incorporation of adolescent patients but will also be shaped by substantial reviews of service models, regional referral pathways, demographic changes and operational efficiencies. The impact of the changes in age limits will require to be incorporated into, and subject to, these exercises which will in turn materially affect the final workforce configuration of the new hospitals

### *Age Appropriate Services*

The breadth of skill mix and competencies required in order to ensure high quality care for young people in hospital has been described elsewhere in this report. The extent to which such staffing models already exist varies substantially between hospitals, and even between services within some larger hospitals.

It is also true that the way in which the required range of skills and competencies are delivered; the amount of dedicated time required for individual clinical disciplines and the capacity for models of more generic interdisciplinary working in the area of adolescent care will necessarily be different in different settings.

It is however evident that current provision of services such as clinical psychology, youth work and specialist adolescent nursing is patchy, frequently inadequate and sometimes completely absent and material improvement in these areas and the consequent provision of true age appropriate care, will require significant planning and investment.

#### **Recommendation:**

Health Board and Regional Workforce Plans should recognise the range of skills and competencies required for the holistic care of young people in hospital including, in particular, their psychosocial needs.

## **8. Resources**

The specific requirement to raise the age limit of children's hospital services to 16<sup>th</sup> birthday and the wider need to provide age appropriate care to young people will raise significantly different issues for the various Health Boards across Scotland. As a result it is not easy to identify, with any precision, the exact investments necessary for these objectives to be addressed and individual Board areas will require to undertake a local analysis of the implications in the context of their existing services and facilities.

It is however possible to identify the principal areas in which the change in the age limit and the provision of appropriate adolescent services and facilities will require accompanying investment.

### *Transfer of Services*

The impact of the change in age limits is seen most explicitly in Edinburgh and Glasgow where the 13<sup>th</sup> birthday is still utilised as the cut off for admissions to the respective children's hospitals except in the case of a few specialist services or children with chronic pre-existing conditions.

In both cities it is anticipated that the move to include all children and young people up to the 16<sup>th</sup> birthday within the children's hospital service will be addressed to the opportunities inherent in developing new children's hospitals. Existing work undertaken as part of the new hospital planning process suggests that, assuming no other changes pertain, the transfer of all 13-15 year old patients currently cared for in the adult sector to the children's hospitals in Edinburgh and Glasgow will result in approximately 10% increase in surgical procedures, 10% increase in in-patient admissions and a 5-6% increase in bed days<sup>18</sup>.

The case mix involved will largely comprise routine secondary care with many of the high cost/low volume activity for this age group already incorporated into the children's hospitals. It is however equally true that although this change does not involve any new activity the capacity to extract and transfer the costs associated with this patient group, most of whom occupy beds scattered throughout the adult units, will be limited. The overall adult bed model should however demonstrate a small corresponding reduction.

As mentioned above the transfer of this activity will however take place in the context of the much wider planning exercises for the two new children's hospitals which will include an emphasis on service redesign, reduced lengths of stay, increased day case rates and enhanced operational efficiency. The net resource effect of the introduction of the new age limits is consequently difficult to predict at this juncture.

Comparable shifts in activity will be experienced in out-patient and A&E departments with some services, such as fracture clinics, coming under particular pressure. The opportunity to mitigate changes in workload through service redesign may be less available in these ambulatory care services and there is therefore likely to be a requirement for a net proportionate increase in staff and allied resources which will extend to associated support services such as diagnostic imaging.

The situation in other Health Boards will vary depending on their starting points in terms of existing arrangements and the model of care and pattern of accommodation they elect to adopt. However where the introduction of the new age limit will require a net shift in patient activity from adult to children's services this will require to be appropriately resourced across the range of clinical areas and services implicated.

The recommendation elsewhere in this report that consideration should be given to delaying transfer to adult services until the young person has reached suitable maturity will also increase use of children's hospital resources and will require to be taken into consideration in Health Board planning.



### *Provision of Facilities*

Description has already been provided with regard to the types of facilities and accommodation required to support high quality adolescent care. How these requirements can be addressed will differ from hospital to hospital and will be materially influenced by the adolescent activity patterns and the services and facilities already in place.

The new hospitals planned for Edinburgh and Glasgow provide an exciting opportunity to incorporate purpose built accommodation from the start and options for adolescent units are actively being considered in the respective planning processes. In other hospitals different solutions will require to be identified to adapt or extend existing facilities. These choices will, in turn, be influenced by the model of care adopted including, in particular, the age limits for any adolescent provision.

One aspect of the facilities required is the provision of equipment and infrastructure to enable appropriate access to the internet, e-mails and phone calls as well as other media connections. This kind of provision, which is important for educational as well as psychosocial reasons, is increasingly incorporated in any new build accommodation but, where necessary, individual Boards will also need to assess the implications of providing such services in existing facilities.

Over and above the capital costs involved in installing such equipment and related facilities, consideration also has to be given to the resourcing of the running costs which can be significant depending on the procurement and provision arrangement. This raises issues relating to the extent to which such costs should appropriately be borne by the NHS, what it is reasonable to expect a young person or their family to fund and how the needs of those from financially disadvantaged backgrounds can be addressed in order to avoid inappropriate patterns of inequity.

These issues are pertinent to adult patients but have particular relevance in regard adolescent facilities given the importance of peer group influences, conformity and self-esteem.

In some hospitals in the UK charitable sector support has facilitated support to some of these issues. Individual Health Boards will however require to make policy decisions depending on the local situations which pertain.

### *Equipment*

Particularly, and possibly exclusively, in respect of the specialist children's hospitals the inclusion of all patients up to the 16<sup>th</sup> birthday will raise a number of specific equipment issues, particularly for surgical care. Although children's hospitals already provide care for a number of adolescent patients the increased number of physically mature patients will necessitate a corresponding increase in the availability of a range of larger surgical instruments and theatre packs.

There will also be a shift in the frequency of certain surgical procedures in some specialities, for example orthopaedic surgery, which will require appropriate equipment provision. In some cases, particularly involving relatively unusual clinical scenarios, these issues may be addressed in collaboration with the co-located adult services but in others an investment in new equipment will be required.

The more frequent treatment of a physically mature cohort of patients may also be reflected in other equipment requirements as diverse as ultrasound probes and ward beds. These issues will require to be identified and addressed within individual hospital departments depending on predicted changes in clinical activity and patient mix.

### *Staff Skill Mix*

Aside from the staffing implications inherent in moving patient activity in accordance with the implementation of the new age limits this report has also identified a number of specific skills and support services that are required to ensure good adolescent care including clinical psychology, youth work etc.

Inevitably the volume of adolescent activity will have a major influence on how such support is best provided. In many hospitals the creation of full time posts will not be necessary or justifiable and alternative solutions will require to be identified, for example part time appointments, posts shared with community services or other hospitals or staff trained to offer more generic skills.

A number of Health Boards already provide some of these services but significant further investment is required if an equitable and adequate range of support functions are to be available throughout Scotland.

### *Training*

As has been identified elsewhere there may be a number of specific clinical issues raised by the change in age limits which will require individuals or clinical teams to undertake some focused additional training. It is not currently anticipated that the volume of additional training required will be extensive and it would seem reasonable to assume that this matter should be addressed within existing Health Board allocations for staff development and training.

The wider issue of up-skilling the staff providing adolescent care in respect of the generic skills involved in caring for young people will be the subject of a Training Needs Analysis conducted by NHS Education Scotland and due for completion in Spring 2008. The output of the TNA should identify the number of additional staff who would benefit from additional training and also the training options available including the possible availability of good on-line packages.

Until the completion of the TNA it is not realistic to quantify the resource implications inherent in procuring or providing such training or in releasing staff to be trained but

some resource allocation will undoubtedly be necessary if staff are to be adequately skilled to confidently address the particular issues raised in providing adolescent care. In that regard, although this report has largely focused on hospital care the issues covered by a generic training package will be relevant to community and Primary Care Staff who have significant interaction with young people and consideration will have to be given as to how any identified training packages can and should be rolled out across NHS Services

## Conclusion

Adolescence is a distinctive stage characterised by change and development in every area of an individual's life. The fundamental nature of these changes makes them inextricably linked to the ways in which young people experience and react to illness and perceive and respond to health care including, in particular, admission to hospital.

The need to ensure that health care services and facilities for young people, and the staff who provide them, reflect the particular requirements of this age group have been acknowledged for many decades. In practice however the provision of age-appropriate care has been accorded low priority by the NHS across the UK with most adolescent hospital patients still being cared for in facilities primarily focused on the very young or on older adults.

The change in the age limits for children's hospital facilities to the 16<sup>th</sup> birthday, addresses a significant discrepancy between Scotland and most of the countries that we would view as our natural comparators. This move of itself, however welcome, will be of limited benefit if it is not progressed in parallel with a genuine commitment to offer young people patterns of service, care and accommodation designed to address their particular needs.

Taking this forward not only requires an investment in facilities and training but also a shift in attitude both in front line clinical staff and also in those who plan and manage services. This is particularly, and perhaps understandably, true within the adult hospital sector where adolescent patients form a numerically small element of the overall workload with services inevitably skewed towards the health care demands of an aging population.

Unless there is a genuine recognition of adolescence as a developmental stage with specific requirements in terms of health care provision, and a willingness to think and plan outwith traditional models of service, the necessary changes will not occur.

**Recommendation:**

The SGHD, in partnership with the Royal Colleges in Scotland, should sponsor a national symposium in 2008 designed to foster engagement and discussion across the NHSiS on the provision of hospital care for young people.

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## **Appendix A Remit and Membership of Age Appropriate Care Working Group**

### **Remit:**

To review the implications of raising the age limit for children's hospitals in Scotland and to offer advice and recommendations as to how this can be enacted in ways which will enhance hospital services for young people while maintaining the highest clinical standards.

This will involve –

- Identifying anticipated changes in the patterns of clinical presentations to children's hospital services and the associated implications for service delivery and staff training
- Exploring best practice models of hospital care for adolescents and how these might be appropriately applied within the NHS in Scotland
- Identifying the training needs inherent in ensuring that staff in children's hospitals are equipped to address the specific emotional, social and legal requirements of young people and working with NHS Education Scotland to consider how these needs should be addressed
- Identifying the practical implications of re-organising services and patient journeys to enact a change of age limits within a Health Board area
- Identifying the implications of a change of age limits for other services accessed by young people in hospital including, specifically, education
- Reviewing the interface between adult services and those provided for children and young people and making recommendations regarding best practice in transition care
- Undertaking the above tasks in ways that take cognisance of both DGH and specialist children's hospital services and also the opportunities offered by the new hospital developments planned for Edinburgh and Glasgow

## Membership of Age Appropriate Care Working Group

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RHSCG	Royal Hospital for Sick Children, Glasgow
SCCCSS	Scottish Colleges' Committee for Children's Surgical Services
SEAT	South East and Tayside
SGHD	Scottish Government Health Directorates
SPENS	Senior Paediatric Educationalists and Nurses, Scotland