Healthcare Policy and Strategy Directorate

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Address list attached



May 2009

Dear Colleague

HOSPITAL SERVICES FOR YOUNG PEOPLE IN SCOTLAND

Please find enclosed your copy of the Hospital Services for Young People Report which was published as guidance for NHS Boards on 5 May 2009.

Following the commitment to raise the age limit for children's hospitals from the 13th to 16th birthday, the *National Delivery Plan for Children and Young People's Specialist Services in Scotland* contained a commitment to publish guidance on age appropriate care arrangements for young people who require to spend time in hospital.

This report contains recommendations for NHS Boards and their regional planning partners to ensure that the care they provide for young people meets their particular needs. The report also highlights the need for effective transition arrangements with a recommendation that transition should happen at an appropriate developmental stage for the young person.

Chief Executives and Directors are invited to draw this letter and report to the attention of all with a responsibility for the provision of these services.

Further copies of this letter and the report can be found on the Scottish Government website at www.scotland.gov.uk/Publications/2009/04/30132716 and all enquiries regarding the report should be directed to Gillian Garvie (Gillian.Garvie@scotland.gsi.gov.uk) or by telephoning 0131 244 2272.

Yours faithfully









Address List

Chief Executives, NHS Boards

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COSLA

Scottish Health Promoting Schools Unit

Child Health Commissioners

National Delivery Plan Implementation Group

Age Appropriate Care Working Group









BETTER HEALTH, BETTER CARE Hospital Services for Young People in Scotland



BETTER HEALTH, BETTER CARE Hospital Services for Young People in Scotland

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Foreword



Traditionally, hospital services have tended to be focussed either on children or adults. As a result young people, during their adolescent years, often have to depend on services and accommodation primarily designed for much younger or older patients.

As part of the Scottish Government's commitment to patient-centred care, we recognise the importance of ensuring that our young people are able to access facilities and patterns of care that take specific account of their particular needs. As a result, following on from existing proposals to raise the age limit for children's services from the 13th to 16th birthday, the *National Delivery Plan for Children and Young People's Specialist Services in Scotland* included an undertaking to publish guidance on hospital facilities for young people.

This guidance, which is targeted at all hospital services which admit young people, highlights a number of issues which need to be taken forward. We need to ensure that hospital staff are properly trained to meet the needs of young people; that educational support is readily available for young people, particularly those who require frequent or prolonged hospital admissions, and that the hospital setting is able to meet the social, recreational and developmental needs of young people. We also need to have in place effective arrangements that support transition to care in the adult sector.

In developing this guidance we have been greatly helped by the views of young people from across Scotland. I expect NHS Boards and Regional Planning Groups to continue this dialogue as this guidance is taken forward.

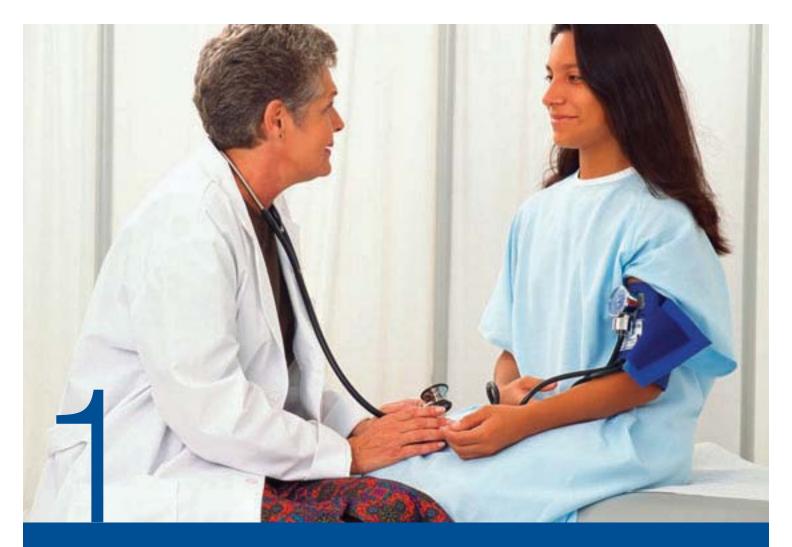
Nicola Sturgeon

Deputy First Minister and Cabinet Secretary for Health and Wellbeing

2. Pa Sturgeon

Executive Summary

- Young people make up 10% of the Scottish population and are responsible for around 4% of hospital admissions (49,000 per annum)
- The specific developmental, emotional and psychosocial needs of adolescent patients are well recognised but have traditionally been poorly addressed by the hospital services and facilities provided in the UK
- The increase in the age limit for children's hospital services in Scotland to the 16th 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
 effective collaboration 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 a need for hospitals to explore innovative solutions, informed by key principles, that give priority not only to the clinical care of adolescent patients but also their developmental, psychosocial 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, structured and appropriately timed
- 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
- The development of services and facilities for young people should be accompanied and informed by effective engagement with young people and their families.



Introduction

Introduction

'Adolescents have distinctive and different needs from both child and adult patients'

At Home in Hospital, Scottish Office (1993)

- 1. 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.
- 2. Conversely, the self-same 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 psychosocial complications that often accompany any chronic illness during this period.
- 3. 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.
- 4. 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.
- 5. 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. Many of these issues are addressed in the General Medical Council guidance on the care of children and young people published in 2007.¹

Age Appropriate Hospital Care

- 6. For all the reasons outlined above 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.²⁻⁷ 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.
- 7. In practice, progress has been slow and incomplete. Significant emphasis has been placed on the development of adolescent services in other parts of the world including Australia and Scandinavia but this has not been reflected in the UK. A survey of adolescent service provision in the UK (excluding mental health facilities), undertaken by the Royal College of Nursing in 2002,8 identified only 13 dedicated adolescent wards and 5 adolescent oncology units. None of these were in Scotland.

- 8. In 2004 the Health Care Commission *Patient Survey Report Young Patients*⁹ 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.
- 9. A more recent review of the Young Patient Survey¹⁰ 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.

'... 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'

Scottish Context

- 10. 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.
- 11. By way of response, the National Framework for Service Change in the NHS in Scotland Building a Health Service Fit for the Future (2005)¹¹ recommended that:
 - NHSScotland adopts the guiding principle that the age for admitting children and young
 people to acute care in paediatric facilities is up to their 16th birthday dependent on
 their clinical need and patient choice
 - 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.
- 12. These recommendations were reinforced in the subsequent *Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland* (2007).¹²
- 13. In order to progress these proposals, an Age Appropriate Care Working Group (AACWG) was established as a workstream of the National Steering Group for Specialist Children's Services (Annex A). The report and recommendations of the Working Group were included in the consultation exercise for the *National Delivery Plan for Children and Young People's Specialist Services* undertaken in 2008.

[†] All quotes used are from young people consulted for the National Delivery Plan

- 14. The consultation responses demonstrated strong overall support for the need for hospital services and facilities specifically targeted at the needs of young people. These responses (www.scotland.gov.uk/nationaldeliveryplanconsultationsummary) have informed both the National Delivery Plan, 13 which was published in January 2009, and this revised report which is now issued as guidance for NHSScotland.
- 15. Whatever improvements are made within children's and adult services regarding the care of young people there will still be a requirement to ensure that the transition to adult services of young people with long-term conditions is recognised as a vital element of the patient journey. While not primarily setting out to address issues relating to transition, this report clearly emphasises the importance of good practice in this area and signposts relevant guidance. This includes, in particular, the recent report published by the Royal College of Physicians, Edinburgh, *Think Transition: Developing the essential link between paediatric and adult care* (2008).¹⁴

Adolescent Mental Health

16. The one specialty which has, for many years both in Scotland and elsewhere, recognised the importance of dedicated adolescent hospital facilities is psychiatry. Scotland already has in-patient adolescent units in Glasgow, Edinburgh and Dundee and arrangements to further increase bed numbers are being taken forward in response to the recommendations in the Child Health Support Group report, *Inpatient Working Group – Psychiatric Inpatient Services* (2004).¹⁵ Against that background this report has not focussed on adolescent mental health although many elements of the report will be applicable to service provision in this specialty.

Terminology

- 17. Adolescence is a developmental stage in life and not 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.
- 18. Bridging the Gaps (2003),² the report of an Intercollegiate Working Party on Adolescent Health, 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.



Current Situation in Scotland

Hospital Activity

19. Of the 1.28 million hospital admissions annually in Scotland (in-patients and day cases) around 4% (49,000) are for patients aged from 12-19 (Table 1).

Age	Emergency	Elective	Transfer	Day Case	Total
12-15 years	10,817	3423	1122	6003	21,365
16-19 years	14,050	3930	1872	7927	27,778

Table 1 – Average annual admissions by age and admission category (excluding obstetric and adolescent psychiatry admissions)[†]

- 20. Inevitably, these admissions are spread across the full range of medical and surgical specialties. A significant percentage of admissions falls in the categories of general medicine and medical paediatrics (23%) and general or paediatric surgery (17%). Other specialties that have relatively high levels of hospital activity in adolescents include orthopaedics (11%), ENT surgery (9%), haemato-oncology (4.5%), oral surgery (4%), plastic surgery and gynaecology.
- 21. 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 (DGH) around the country. Practice in this regard will vary depending on existing age limits (see below).
- 22. 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, pending planned new hospital builds, the age limit of the 13th birthday is consistently applied for new admissions unless there is a specific specialist requirement for care at the designated children's hospital.
- 23. In addition to the above in-patient activity there are around 93,000 new out-patient appointments (including obstetrics and psychiatry) for patients aged 12-19 each year (12-15 years 42,786; 16-19 years 50,064).[†]
- 24. National data for accident and emergency attendances by age is not available, however, evidence from a 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 13-15 years.

[†] Based on Information Services Division data for financial years 2005/06 and 2006/07

Current Hospital Admission Policies

- 25. 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 specialty services throughout the country.
- 26. A survey undertaken for this report showed that the upper age limit of the larger dedicated children's units and hospitals varied from 13th to 16th birthday (Table 2).

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

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

27. This situation is evolving. The Royal Aberdeen Children's Hospital anticipates raising the age limit to 16th birthday during 2009. In Edinburgh and Glasgow plans to move the age limit for their children's services to the 16th birthday will be progressed in conjunction with the development of their new children's hospitals, currently scheduled to open in 2013.

Dedicated Adolescent Facilities

- 28. Outwith adolescent mental health, 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. The age limit for this unit straddles from late teens to young adults up to around 24 years of age.
- 29. A survey conducted by Action for Sick Children (Scotland) in 2000,¹⁶ found that 44% of all the wards admitting patients aged 0-18 offered 'special facilities' for adolescents although these may take the form of equipment (e.g. computers etc.), day room space etc. as opposed to dedicated in-patient accommodation.

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

In Borders General Hospital the Paediatric Ward has a 3-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.

The recently reprovided children's unit in Crosshouse Hospital includes a dedicated area with 4 cubicles and a sitting room for adolescent patients. Patients accommodated in this area may be under the care of clinical teams from both paediatric and adult services.

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

The Royal Hospital for Sick Children, Glasgow, has a Young People's Service. Led by a Nurse Specialist, the team includes a part-time Youth Worker and part-time Activities Coordinator and works with a range of clinical staff including a link nurse for each ward or department. In addition to working directly with adolescent patients the team also raises awareness of adolescent care issues and ensures young people are involved in service design and evaluation.



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

Philosophy of Care

- 32. 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.
- 33. In practice, the range of circumstances in which hospital care will be provided to young people will vary enormously across the spread of geographic locations and hospital services represented in Scotland. Although no single pattern of services, facilities or accommodation will be appropriate or deliverable, 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.
- 34. 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.
- 35. Key Principles

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 and privacy
- 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 their clinical care. Where clinical considerations and service configurations permit there should be opportunity for the young person to exercise choice regarding the facilities to which they are admitted and the services which they access.

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 healthy behaviours and lifestyle choices in ways that are appropriate for this age group.

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.

**Specifically, in taking forward the recommendations in this guidance, NHS Boards should ensure that the planning of new or amended facilities and services is undertaken in close consultation with the young people who will use them.

36. You're Welcome – making health services young people friendly (Dept. of Health, 2007)¹⁸ and the European Association for Children in Hospital Charter and Annotations (2002)¹⁹ offer further guidance on quality criteria that reflect best practice in both community and hospital services for adolescents.

Training

- 37. The change in the upper age limit for children's hospitals, and the accompanying focus on adolescent care, raises two separate issues in respect of staff training:
 - (i) Generic
 - (ii) Clinical

Generic Training

38. 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. Young people consulted about the National Delivery Plan strongly supported the need for staff to learn more about working with their age group.

'Please don't treat us like we're younger than we really are.'

'They need to make their ears bigger – so they can listen! Explain things so I can understand.'

- 39. 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.

- 40. A number of professional training programmes already cover adolescent care including the Royal College of Paediatrics and Child Health (RCPCH) core competencies for paediatric medicine and the curriculum for children's nursing.
- 41. Other clinical disciplines do not routinely incorporate adolescent training in their curricula and equally there will be staff that have previously received training in adolescent care which has not been utilised in the more recent past.
- 42. To ensure high quality age appropriate adolescent care throughout Scotland there is an initial need to:
 - Determine the core competencies which staff involved in adolescent care should be expected to display
 - Ascertain the potential number of staff whose on-going roles involve adolescent care and who lack relevant training
 - Identify any existing training programmes or material which could be accessed in order to address generic staff training needs.
- 43. NHS Education Scotland (NES) have undertaken a preliminary Training Needs Analysis during 2008-09. Informed by the output of the Analysis, there will be a need to identify and roll-out an appropriate training programme to relevant staff. In that regard the e-learning package recently developed by the RCPCH, in collaboration with other professional bodies and education providers (www.rcpch.ac.uk/Education/Adolescent-Health-Project) is designed for use by various clinical disciplines and offers a potentially useful vehicle for training in adolescent care.

We will:

Require all NHS Boards to ensure, by 2013, that all staff routinely dealing with young people have had appropriate training.

Clinical Training

- 44. The need for specialty, 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.
- 45. 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, currently delivered in the adult sector, will transfer to the children's hospital.
- 46. 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.

- 47. 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, or complicated by, self-harm or drug or alcohol abuse
 - Conditions directly related to puberty and growth.
- 48. 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.
- 49. 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.
- 50. There is no current evidence of any specific or widespread training issues 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 specialties 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.
- 51. Where there is a perceived 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 are 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 a range of medical and surgical specialties. 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.
- 54. Such an approach may, in part, be addressed by having a nursing team drawn from different specialty 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.

We will:

Ask NHS Boards to ensure that, in implementing the change in age limits:

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.

Appropriate arrangements are put in place to provide the required training.

Full advantage is taken of the opportunities provided by co-location for collaboration between adult and paediatric services in delivering care to young people.

Facilities, Accommodation and Models of Care

- Even following the full introduction of the new age limits for children's services it will remain true 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
 - A children's unit within a District 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, maternity units, DGHs with no paediatric unit)
 - most patients aged 16 and over
 - some adolescent psychiatry patients are still admitted to adult wards
 - Adolescent psychiatry units
 - most patients aged 12-18 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 issues relating to case mix and activity levels. 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 setting into which young people are admitted.

In-patient Accommodation

- 57. In 1993 the Scottish Office Home and Health Department 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.⁶
- 58. Existing guidance contained in reports such as *Youth Matters* (1998)⁷ and *Bridging the Gaps* (2003)² sets out the key principles which should inform the development of any adolescent in-patient 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:
- 59. 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.
- 60. **Single Rooms:** Largely driven by concerns about infection control there is an increasing move towards in-patient hospital accommodation being provided in single rooms. This is particularly true when new facilities are being developed.²⁰
- 61. Single rooms address the desire young people often have for privacy but, in contrast, may hinder the socialisation that plays an important role in their lives. Such socialisation may have the added advantage of preventing the pattern of withdrawal and depression that can accompany periods of ill health and can be aggravated by isolation.
- Reflecting these competing considerations, the preferences of young people consulted for the *National Delivery Plan*, ¹³ and relevant voluntary sector organisations involved in young people's healthcare, favoured a mix of shared and single accommodation. The planning of any adolescent facility needs to give due consideration to these different requirements and should include engagement with the potential users.
- 63. Whether shared or single accommodation is provided opportunity should be taken, wherever possible, to facilitate the appropriate 'personalisation' of their bed space by young people, particularly where a prolonged stay is anticipated.

- 64. **Recreational and Social Facilities:** A recurring finding in surveys of young people in hospital is concern at 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.
- 65. 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.
- 66. 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 wards) run counter to their normal life and significantly increase the sense of hospitalisation and loss of independence.
- 67. While recognising the constraints regarding the safe provision and preparation of food in hospitals, access to appropriately managed self-catering facilities (or equivalent) can significantly enhance the normalisation of a young person's hospital experience and the likelihood of adequate dietary intake.
- 68. **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.
- 69. **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.
- 70. The circumstances in which adolescent facilities are developed may determine, in large measure, the age range accommodated. 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). Correspondingly adolescent facilities provided within a children's hospital or unit will focus primarily on younger adolescents, principally under 16 years.
- 71. However, just as 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.

- 72. 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. Depending on local circumstances and activity patterns, there could be opportunities to extend such age limits slightly in either direction.
- 73. **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.
- 74. 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 able to benefit from such facilities will vary considerably from individual to individual.
- 75. It is not realistic to offer any 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 that are often at variance with life outwith hospital. This can be particularly noticeable in the case of adolescent patients making hospitalisation a very abnormal experience.
- 77. 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 and the pattern of meal times as well as the flexibility to accommodate individual need and preferences. This is not arguing for a laissez faire approach but for an appropriately structured routine.
- 78. 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 represent a period of maximum boredom reported by young people in hospital.
- 79. 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.

- 80. 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.
- 81. **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.
- 82. 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. Such arrangements offer the balance of accessibility and independence which many young people feel best meets their needs.
- 83. **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.
- 84. 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 available both in shared recreational space and at bedside level.
- 85. 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.
- 86. 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.
- 87. 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

- 88. 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 specialty based services and the age boundary between children's and adult services (even where this operates at or around the 16th birthday).
- 89. **Specialty Based Services:** The distribution of patients within a hospital is frequently determined by the nature of their illness and therefore 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 desire 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.
- 90. 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.
- 91. Clearly clustering adolescent patients together may require a different approach to the delivery of specialist care. 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 multi-specialty unit.
- 92. Consultation with young people demonstrates a strong preference for their being accommodated with their own age group rather than within specialty 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.
- 93. **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 change in age limits to the 16th birthday, 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.
- 94. 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 evidence²¹ 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.

- 95. 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 opens up different opportunities to provide age appropriate accommodation and services.
- 96. 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 In-patient and Short-stay Facilities

- 97. 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 in-patient areas.
- 98. 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 co-located ambulatory, day care and maternity services on an 'outreach' basis.

Out-patient Facilities

- 99. The volumes and patterns of attendance of young people at out-patient clinics will vary substantially between hospitals and also between specialties within the hospital. It is also true that many aspects of out-patient accommodation are reasonably generic across the spectrum from children through to adults.
- 100. The principles expressed 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 particular young people frequently report finding the design and content of waiting areas largely focussed on the needs of younger children.
- 101. In practice the pattern of out-patient provision for young people may be as important as the environment. 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.

We will:

Ask NHS Boards to:

Review the pattern and volume of adolescent admissions to identify opportunities for creating adolescent facilities.

Consider the possibility of creating adolescent facilities accessed by both adult and children's services where this is appropriate and enhances viability.

Ensure the key elements of age appropriate care are addressed in all settings where young people are routinely admitted.

Staffing

- 102. As with the issues relating to the provision of facilities and accommodation, 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.
- 103. Common to any staffing model is the key requirement that all clinical staff 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

- 104. Being defined by age rather than clinical specialty adolescent units are almost always multi-specialty in their case mix (possible exceptions include teenage cancer units). Concerns are often expressed regarding the feasibility of developing satisfactory specialty-specific skills within the nursing pool supporting such a unit, however, the experience of existing successful adolescent units suggests 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 specialties.
- 105. There may be some highly specific skills that cannot realistically be 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.
- 106. 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.

107. 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 regularly 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

- 108. Most medical staff dealing with adolescents will do so in respect of their particular specialty service. As such a key requirement will be to ensure that they have the appropriate clinical skills to respond to any change in practice resulting from the raised age limits.
- 109. Where a dedicated adolescent unit is developed there will also be a need for medical staff to adapt to a different model of in-patient care which will cross traditional specialty boundaries and will itself require to flexibly accommodate the clinical and organisational requirements of multiple specialities.
- 110. The development of adolescent medicine as a specific sub-specialty 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 well as providing clinical leadership in developing adolescent services.
- 111. The Action Framework¹² also recommended 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. In practice there is no reason why such individuals could not also fulfil a regional role.

Allied Health Professions

112. 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

- 113. 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 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.
- 114. 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.
- 115. 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

- 116. 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.
- 117. 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.
- 118. 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.
- 119. 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

120. 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.

We will:

Ask NHS Boards to:

Develop sustainable models to deliver the range of competencies and skill required to address the psychosocial, developmental and spiritual needs of young people.

Ensure that all hospitals admitting significant numbers of young people designate a local clinical lead (or leads).

Education

- 121. The provision of healthcare to children and young people includes the inherent responsibility to work with the relevant authorities to minimise the impact of prolonged, recurrent or chronic illness on the individual's educational achievements.
- 122. This requirement is particularly pertinent in adolescent care where the loss of educational time may have a significant 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.
- 123. The Standards in Scotland's Schools Act (2000) and subsequent guidance issued in December 2001²² detail 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, provided 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 days then teaching should proceed immediately'. This latter stipulation is of particular importance for young people who require recurrent admission, even for relatively short periods.
- 124. 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.

- 125. 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 requires to be agreed at a local level and needs to be able to accommodate different clinical situations depending on the young person's pattern of treatment, mobility etc. They should however be informed by a number of key principles:
 - Wherever possible, and particularly in larger units, dedicated and appropriately
 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.

We will:

Ask NHS Boards to ensure that all units admitting young people:

Work with the hospital teaching team and education authorities to maximise educational provision.

Have clear procedures for prompt referral to the relevant educational provider of school age patients whose admission is anticipated to exceed 5 days.

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."

Society for Adolescent Medicine (2003)

126. 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. It has increasingly been recognised and accepted that the safe and successful transfer of care involves a well planned and coordinated transition process with which the young person and their family is fully engaged. In contrast poorly organised transition can be associated with non-adherence to treatment and non-attendance for follow-up and care, behaviours that can have a significant effect on morbidity and even mortality. 23, 24

'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.'

- 127. Effective transition raises additional difficulties when the young person is socially vulnerable or has a life-limiting condition. In the latter circumstance good transitional arrangements may need to incorporate 'dual planning' planning for the death of the young person as well as planning their move to the adult sector.²⁵ These issues are sometimes complicated by adult services and staff having little experience of conditions which, in the past, rarely permitted survival beyond childhood.
- 128. The importance of well-planned transition and the consequent successful transfer of care between children's and adult services has been reflected in a number of recent publications including 'Transition: Getting it Right for Young People' (2006) and 'Transition: Moving on Well' (2008) produced by the Department of Health.²⁵⁻²⁸
- 129. In Scotland, the Royal College of Physicians, Edinburgh (RCPEd) has recently published an extensive review of transition care, *Think Transition: Developing the essential link between paediatric and adult care* (2008),¹⁴ which provides a further valuable source of current good practice in this area. The report covers both generic issues and the way these are reflected in a number of specialty-specific settings renal, cystic fibrosis, diabetes and cancer follow-up. In particular the review has identified the value of a 'key worker' or equivalent who can support the young person and their family during the transition process.

Age at Transfer

'Ideally children and young people's services should be prepared to provide healthcare for young people until they have largely completed the development tasks of adolescence.'

Transition: getting it right for young people, Dept. of Health (2006)

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

- 131. Evidence gathered by the RCPEd working group suggests that young people's preference favours care remaining with the paediatric service provider through the principal stages of adolescence with formal transfer to adult services taking place around, or even beyond, 18 years of age. Such an arrangement aligns healthcare more closely with other markers of the transition to adult life, particularly education and employment.
- 132. Ultimately, transfer from paediatric to adult services should be the culmination of a period of planned transition care. There will always need to be sufficient flexibility to accommodate individual maturity, patient choice and, in some instances, specific local service issues. The adjusted age limits, including flexibility regarding 16-18 year old patients, do however create an opportunity to ensure that the transfer of care takes place at a time that does not further complicate the challenges already inherent in managing a young person with a chronic condition through their adolescent development.

Reciprocal Adult Services

- 133. Effective transition is inevitably dependent on the existence of a complementary adult service to which transfer of care can take place. As medical advances increasingly support the survival into adulthood of children and young people with complex and life-limiting conditions, clinical demands are created which existing adult services are not configured to address.
- 134. In recognition of this emergent and growing issue a short-life working group has been established as part of the implementation process for the *National Delivery Plan* to explore potential models of care for this patient population.

We will:

Ask NHS Boards to ensure that care pathways for young people with long-term conditions:

Incorporate well-structured transition arrangements that accord with best-practice guidance.

Take advantage of the flexibility offered by the revised age limits to defer formal transfer to adult services until the most appropriate developmental stage for the young person.

Give consideration to the benefits of identifying a key worker to support each young person through the transition process.

Workforce

135. Although this report is focussed 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

- 136. Adjusting the upper age limit for children's services to the 16th birthday will impact differently across the spread of Scottish hospitals given the current variability in the admissions arrangements for adolescent patients, particularly those aged 13-15 years.
- 137. 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.
- 138. 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 NHS 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 assess the impact on workload and the consequent staffing requirements in terms of numbers and skill mix.
- 139. In that regard it is clearly relevant that the incorporation of all 13-15 year old patients into 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 for these hospitals will not only need to take account of this additional workload but will also be shaped by redesigned service models and changes in referral pathways, demography and operational efficiency, all of which will collectively determine the final workforce configuration of the new hospitals.

Age Appropriate Services

- 140. 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 guidance. The extent to which such staffing models already exist varies substantially between hospitals, and even between services within some larger hospitals.
- 141. 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.
- 142. 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 truly age appropriate care, will require significant planning and investment.

We will:

Ask NHS Boards and Regional Planning Groups to ensure that workforce plans recognise the range of skills and competencies required for the holistic care of young people in hospital including, in particular, their psychosocial needs.

Resources

- 143. The specific requirement to raise the age limit of children's hospital services to 16th birthday and the wider need to provide age appropriate care to young people will raise significantly different issues for the various NHS 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.
- 144. It is, however, possible to identify the principal areas in which investment may be required.

Transfer of Services

- 145. The impact of the change in age limits is seen most explicitly in Edinburgh and Glasgow where significant numbers of 13-15 year old patients are still cared for in adult wards.
- 146. In both cities it is anticipated that the move to include all children and young people up to the 16th birthday within the children's hospital service will be addressed by 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% more surgical procedures, 10% increase in in-patient admissions and a 5-6% increase in bed days (NHS Greater Glasgow and Clyde Personal Communication).
- 147. 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.
- 148. 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.
- 149. 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. This will extend to associated support services such as diagnostic imaging.
- 150. The situation in other NHS 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. 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.

Provision of Facilities

- 151. The provision of appropriate facilities, in accordance with this guidance, may require accommodation to be adapted or enhanced with associated capital expenditure implications. How these issues are manifest and 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.
- 152. 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.
- 153. 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 NHS Boards will also need to assess the implications of providing such services in existing facilities.
- 154. 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 arrangements. 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.
- 155. These issues are pertinent to adult patients but have particular relevance in regard to adolescent facilities given the importance of peer group influences, conformity and self-esteem. In some hospitals in the UK, charitable sector support has facilitated solutions to some of these issues. Individual NHS Boards will however require to make policy decisions depending on the local situations which pertain.

Equipment

- 156. Particularly, and possibly exclusively, in respect of the specialist children's hospitals the inclusion of all young people up to the 16th 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.
- 157. There will also be a shift in the frequency of certain surgical procedures in some specialties, 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.

158. 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

- 159. 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 and youth work.
- 160. 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.
- 161. A number of NHS 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 NHS Board allocations for staff development and training.
- 163. The wider issue of up-skilling the staff providing adolescent care in respect of the generic skills involved in caring for young people has been the subject of a Training Needs Analysis conducted by NHS Education Scotland which was completed in Spring 2009. The output of the Analysis should identify the number of staff who would benefit from additional training and also the training options available including the possible availability of good on-line packages.
- 164. Until the output of the Training Needs Analysis has been assessed, it is not realistic to quantify the resource implications inherent in procuring or providing such training or in releasing staff to be trained. Some resource allocation will however 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

- 165. 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.
- 166. The need to ensure that health care services for young people, and the staff who provide them, reflect the particular requirements of this age group has 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 focussed on the very young or on older adults.
- 167. The change in the age limits for children's hospital facilities to the 16th 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 accompanied by a genuine commitment, across the NHS in Scotland, to offer young people patterns of service, care and accommodation designed to address their particular needs.
- 168. This must include a recognition that a young person's eventual transfer to adult services must take place at a time suited to their developmental needs and as the culmination of a planned transition programme.
- 169. Central to these processes will be a parallel commitment to engage effectively with young people and their families.
- 170. Taking this forward requires not only an investment in facilities and training but also a shift in attitude both in front line clinical staff and 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.
- 171. Unless there is a genuine recognition of adolescence as a developmental stage with specific implications for health care provision; a willingness to think and plan outwith traditional models of service and an openness to engage with young people themselves, the necessary changes will not occur.

We will:

Host a national conference in 2009 focussing on the provision of hospital care for young people.



References

- 1. General Medical Council (2007), 0-18 Years: Guidance for all Doctors
- 2. Royal College of Paediatrics and Child Health (2003), Bridging the Gaps, Report of an Intercollegiate Working Party on Adolescent Health
- 3. Platt H (1959), The Welfare of Children in Hospital, HMSO
- 4. Committee on Child Health Services (1976), Fit for the Future, HMSO
- 5. National Association for the Welfare of Children in Hospital (1990), Setting Standards for Adolescents in Hospital
- 6. Scottish Office (1993), At Home in Hospital, A Guide to the Care of Children and Young People
- 7. Viner R, Keane M (1998), Youth Matters, Caring for Children in the Health Services
- 8. Royal College of Nursing (2002), National Survey of Adolescent Service Provision, Adolescent Health Forum
- 9. Healthcare Commission (2004), Patient Survey Report Young Patients
- 10. Viner R (2007), Do Adolescent In-patient Wards Make a Difference. Arch Dis Child 92 (Suppl 1): A69
- 11. Scottish Executive (2005), Building a Health Service Fit for the Future: A National Framework for Service Change in the NHS in Scotland
- 12. Scottish Executive (2007), Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland
- 13. Scottish Government (2009), National Delivery Plan for Children and Young People's Specialist Services
- 14. Royal College of Physicians, Edinburgh (2008), Think Transition: Developing the essential link between paediatric and adult care
- 15. Scottish Executive (2004), Child Health Support Group, In-patient Working Group Psychiatric In-patient Services
- 16. Action for Sick Children (Scotland) (2000), Parental Access and Family Facilities in Wards Admitting Children in Scotland
- 17. NHS Scotland (2007), Age and Health Guidance
- 18. Department of Health (2007), You're Welcome making health services young people friendly
- 19. European Association for Children in Hospital (2001), The EACH Charter and Annotations
- 20. Scottish Government (2008), Provision of Single Room Accommodation
- 21. Viner R (2001), National Survey of Use of Hospital Beds By Adolescents Aged 12 to 19 in the United Kingdom. British Medical Journal 322:957-958
- 22. Scottish Executive Education Department (2001), Education of Children Absent from School through III-Health
- 23. Sommerville J (1997), Near misses and disasters in the treatment of grown-up congenital heart patients. J R Soc Med 90: 124-127
- 24. Rianthorvan P, Ettenger R (2005), Medication non-adherence in the adolescent renal transplant recipient. Pediatr Transplant 9:398-407
- 25. Department of Health (2008), Better Care: Better Lives
- 26. Department of Health (2006), Transition: getting it right for young people
- 27. Department of Health (2008), Transition: moving on well
- 28. Viner R (2008), Transition of care from paediatric to adult services. Arch Dis Child 93:160-163



Annex

Annex 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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APA Association of Paediatric Anaesthetists

RCPS Royal College of Physicians and Surgeons

RHSCE Royal Hospital for Sick Children, Edinburgh

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

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