



Royal College
of Physicians



Future
Hospital

On the margins of medical care

Why young adults and adolescents need better healthcare

A report to the Future Hospital Programme of the Royal College of Physicians

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Executive summary

Young adults and adolescents (YAA)* aged between 16 and 25 years are no longer among those considered to be the healthiest alive. Enormous improvements in health for children and young people have been achieved over the past 50 years, but the health of adolescents has shown significantly less improvement than that of any other age group. Mortality among adolescents is now higher than that for all other stages of childhood, except for infants aged under 1 year.¹ Over 20% of YAA aged 13–24 years rate themselves as having a long-standing illness.²

Failure to recognise and meet the health needs of YAA has both immediate and long-term consequences for this group, for their families or carers, and for society: poor healthcare outcomes incur considerable personal costs in this age group with regard to employment, personal wellbeing and quality of life. YAA have the same rights to good healthcare as any other age group, yet health outcomes and reported experiences suggest that they have not been provided with the care and thought afforded to other age groups. Healthcare commissioners, providers and regulators should work to improve healthcare for this group of people.

YAA need special consideration as a patient group that has unique needs and particular vulnerabilities. Clear and accumulating evidence about brain development, combined with what is known about the impact of social transitions that take place during adolescence and early adulthood, confirms that urgent action is required to deliver age-appropriate care to meet the needs of YAA.

There is growing recognition that YAA need extra support during their transition from paediatric to adult healthcare services, but there is patchy implementation of good practice. Only about half of YAA who have childhood chronic disease receive any preparation for this transfer of healthcare.³

The system is failing to meet the needs of YAA because of the inflexibility of services, lack of incentives to deliver innovative and more appropriate models of care, insufficient training of healthcare professionals, poor communication across professional boundaries, and patchy implementation of guidance.

It is vital that the barriers to patient-centred, joined-up care for YAA are removed. This document offers practical advice and guidance that is needed to reshape healthcare to better meet the needs of YAA.

* Young adults are defined as those aged 20–25 years and adolescents as those aged 10–19 years, according to the chief medical officer's definition. Different age ranges are referred to throughout this document, reflecting the inconsistencies in datasets and research (another symptom of the 'invisible' nature of YAA).

Suggestions for improvements in clinical practice

Through conducting an overview of the main health issues faced by YAA and by summarising the challenges to good YAA healthcare, we have produced suggestions for improving clinical practice, which are designed to overcome the barriers and promote the opportunities identified in this report. Each suggestion is targeted at a health-related organisation, public body or healthcare professionals, in order to direct implementation.

1 Improving standards and systems

- 1.1 A national audit of patient care against the 'You're Welcome' criteria should be commissioned in the 16–25-year age group, to allow a baseline against which improvements can be measured (Healthcare Quality Improvement Partnership (HQIP)).
- 1.2 Standards of care for YAA in adult services should use the 'You're Welcome' criteria as a template (Department of Health, working with the National Institute for Health and Care Excellence (NICE)). Local needs assessments of the healthcare needs of YAA should be conducted and used to inform the finance and contracting of services for YAA (clinical commissioning groups (CCGs)).
- 1.3 It should be compulsory to include and publish an evaluation of transition in the overall rating of both paediatric and adult services (Care Quality Commission (CQC)).

2 Service design

- 2.1 Alternative models of care (such as telephone or online review and community-based clinics) should be encouraged. Tariff and other financial and non-financial incentives should be reviewed so that NHS providers are encouraged to use new technology and to engage YAA through new media (Monitor and NHS England).
- 2.2 Decisions about service reconfiguration should always be clinically led and include arrangements for YAA (NHS providers).
- 2.3 Where possible, YAA clinics and services should be developed in tertiary, secondary and integrated care settings. Where this is not feasible, locality-wide healthcare services should develop tiered models of care, for example employing coordinators who are able to advocate on behalf of YAA and to signpost and facilitate access to other services, including primary care.
 - 2.3.1 All healthcare professionals who are likely to come into contact with YAA should be aware of the range of services, such as sexual and mental health services, to which YAA can be referred if required.

- 2.4 Standard operating procedure should apply in all services to ensure that there is a common, defined procedure for treating YAA who are admitted to hospital and to avoid the possibility that YAA fall ‘between the cracks’ of paediatric and adult services (NHS providers).
- 2.5 If clinicians are serving a population that includes a significant proportion of YAA, their job plans should be adjusted to allow adequate time to meet the needs of this group. Clinical pathway design should allow time for information provision and coaching (trust medical directors).
- 2.6 Age-group aggregations that result in clear visibility of YAA service use, satisfaction and outcomes should be adopted nationally by all health service organisations.
- 2.7 YAA, and their families and carers,^{*} should have access to all information relevant to their healthcare and treatment (NHS providers, clinicians).
- 2.8 Services for YAA should be flexible in terms of accessibility and operation, in order to accommodate the different needs and capabilities of YAA (NHS providers).
- 2.9 Evaluation should be integral to service redesign and should allow sufficient time for the accrual of improvement in health and user satisfaction outcomes (NHS providers).

3 Education and training

- 3.1 Training for physicians should include the care of YAA. Curricula and educational programmes should include appropriate content regarding the care of YAA around:
 - effective communication between physicians and YAA
 - the developmental and psychosocial needs of YAA (physical, mental and sexual reproductive health needs)
 - appropriate palliative care for YAA
 - guidance for YAA to enable them to navigate the NHS, including how to involve young people, families and carers in decision-making and healthcare plans.(General Medical Council, Health Education England, Joint Royal Colleges of Physicians Training Board and professional bodies).
- 3.2 Specialties should ensure that aspects of YAA disease that are particular to that specialty are included in curricula and competency frameworks, and are assessed.
- 3.3 All professional bodies should consider how to support the training of healthcare professionals in this area.
- 3.4 YAA should be involved in the training of physicians.

^{*} when appropriate

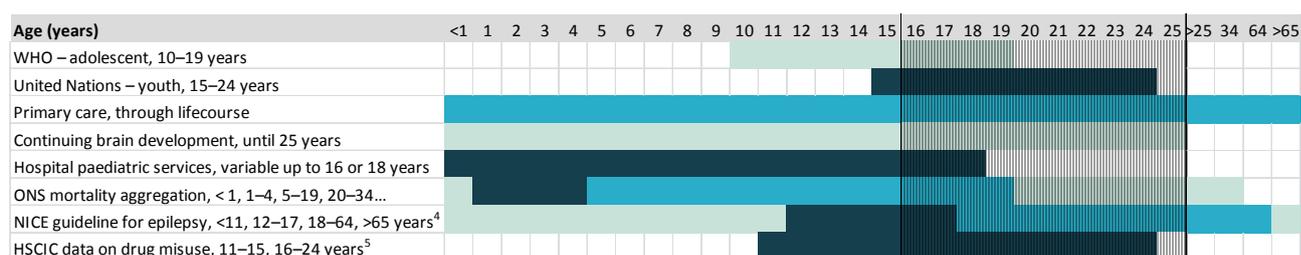
1 Introduction

Why urgent action is needed to improve healthcare for YAA

*The ... health and social care system, that is not working ... is letting down many desperately ill youngsters at a critical time in their lives. We have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve. The system is fragmented, confusing, sometimes frightening and desperately difficult to navigate. Too often instead of helping young people and their parents it adds to their despair. It need not be like this.*³

The NHS has made excellent progress in meeting the particular needs of young children and older people, yet YAA are relatively invisible in the health landscape. It is a challenge even to obtain an accurate picture of the health of 16–25-year-olds as this group, straddling child and adult health providers, is not often clearly distinguished in published outcome data, and thus key issues affecting YAA have little prominence compared with those affecting other vulnerable age groups.³ Data often render those in the 16–25-year age group invisible, being variably aggregated for children or adolescents up to the age of 15, 16, 17, 18 or 19 years, and for adults from 19 to 64 years (Fig 1). This variability makes it extremely difficult to get a clear and specific view of many aspects of the health of YAA patients, and to understand how they use the healthcare system and how they feel about it.

Fig 1: Data aggregation variability (YAA 16–25 years in hatched area).



The CQC report *From the pond into the sea*³ highlights deficiencies in services for YAA. We should not continue to insist that emerging adults are treated like every other adult in the health system when there is very clear scientific evidence that their decision-making skills are still maturing.

Failing to recognise and to meet the health needs of YAA has both immediate and long-term consequences for YAA, their families or carers, and society. At an individual level, the cost of poor healthcare outcomes for YAA who have long-term, chronic conditions is considerable in terms of lost

employment potential, increased disability and shortened lifespan. More globally, only limited data are available on the health economic consequences of the poor provision of services that are developmentally appropriate for YAA. This is a key research need. Two examples of diabetes and renal disease illustrate the wide social and economic impact of poor health outcomes for YAA.

Diabetes:

- Around 70% of childhood type 1 diabetes occurs in adolescence, yet adolescents have poorer diabetes control and more emergency hospital admissions than children or adults because of poor self-management.⁶
- Up to 40% of young adults with type 1 diabetes 'drop out' of adult-oriented medical care after transfer from paediatrics. People who dropped out were subsequently found to experience devastating consequences such as pregnancy loss, blindness, amputation and death.⁷

Renal disease:

- Outcomes in adolescents and young adults with end-stage renal disease remain among the poorest across all age groups, in terms of both rejection of a transplanted kidney and avoidable hospital admissions.⁸
- Renal transplant survival is as much as a third lower in young adults than in children.⁹

This report is a call to arms. It stresses why YAA need to be considered as a defined population. It aims to highlight the limited recognition of the healthcare needs of YAA beyond paediatrics. Furthermore, in the absence of a review of the current health status of YAA and of barriers to appropriate transitional services for YAA, this document hopes to promote the prioritisation of changes that will improve health and social care outcomes for all YAA.

Health outcomes in young adults and adolescents in the UK are often poorer than:

- **those for people in other age groups who have the same problem: for example, in end-stage renal disease, young people are more likely to reject a transplanted kidney and to have avoidable hospital admissions than any other age group**
- **their counterparts in Europe or the USA: for example, young diabetics in the UK are more likely to die from their disease than young European or North American diabetics.**

The Royal College of Physicians' Future Hospital Commission and YAA

In its 2013 report, *Future hospital: caring for medical patients*,¹⁰ the Future Hospital Commission (FHC) set out a vision for healthcare services structured around the needs of patients. While the FHC report focused on the care of acutely ill medical patients, it acknowledged that people's needs are often complex, and that hospital services should be organised to respond to all aspects of physical health (including multiple acute and chronic conditions), mental health and wellbeing, and social and support needs.

The FHC report clearly identified YAA as needing specific services. It identified both the increasing recognition of health issues that affect YAA and the current focus in national policy and guidance around 'transition', but it recognised that implementation of this policy and guidance is patchy. The report also recognised that many young adults over the age of 16 'crash-land', ie they are admitted acutely unwell to a medical unit for the first time. The needs of this group are rarely acknowledged even though they represent a considerable proportion of people using health services. How healthcare professionals manage YAA has a lifelong impact on their health-seeking behaviour. For example, missing a single outpatient appointment in adult services usually means discharge, whereas a further appointment will be given in paediatric services. This approach may disproportionately affect YAA, who then drop out of the system and are lost to follow-up. The consequences are poorer health outcomes and the costly use of emergency services rather than scheduled care.⁶

As a means of improving management of YAA, the FHC recommended:

- additional staff training and competencies to improve management of YAA
- early involvement of the general practice team and specialist staff to help YAA to navigate the health system
- a single point of contact or key person in secondary care who can coordinate other healthcare professionals
- guidance for YAA, their families and carers about what to expect on admission to an adult ward.

This report develops the RCP's continuing commitment to improving care for people in this transitional age group who have medical problems. It will focus on:

- provision of healthcare services for YAA with chronic disease that developed earlier in childhood, who leave paediatrics and move to services provided in an 'adult' health setting
- YAA who enter the healthcare system without experience of paediatric services.

This report outlines the problems that confront both groups, identifies barriers to good care and suggests what needs to be done to improve the situation for this almost-invisible population.

2 How healthy are YAA in the health service?

Numbers of YAA

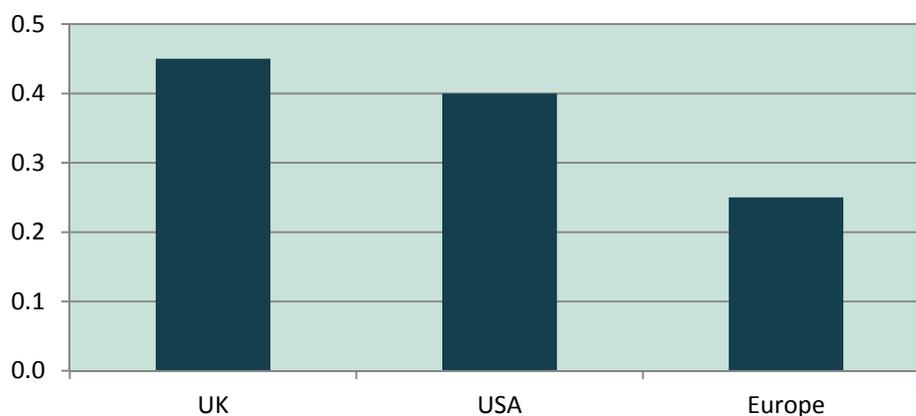
National census population data show that 12% of the UK population is aged between 16 and 24 years; exactly the same percentage as those aged over 70 years.¹¹ At least one in five young people aged 13–24 years rates themselves as having a long-standing illness.² Many more have healthcare needs related to sexual and reproductive health, injuries and mental health problems.

At least one in five young adults and adolescents aged 13–24 years rates themselves as having a long-standing illness.²

Mortality

Enormous improvements in health for children and young people have been achieved over the past 50 years, but the health of adolescents has shown significantly less improvement than that of any other age group. Decreased mortality for those aged 1–9 years has resulted from improvements in nutrition and the management of infection, whereas improvements in mortality in the 10–24-year age group, more related to injury (intentional and non-intentional) and non-communicable disease (such as diabetes, epilepsy, cardiovascular disease, asthma and mental health disorders), are substantially smaller.⁶ Furthermore, other developed countries outperform the UK in relation to numbers of deaths among YAA from non-communicable diseases, including cancer and diabetes (Fig 2).

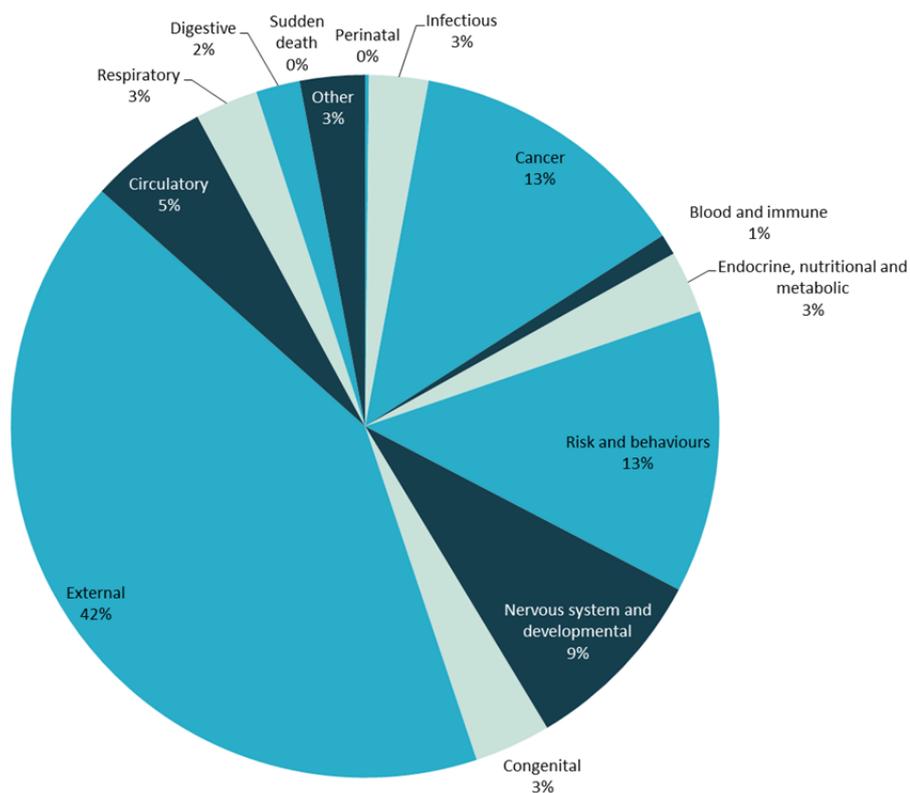
Fig 2: Deaths from diabetes per 100,000 population aged 15–24 years in 2010.¹²



The overall 5-year survival rate for cancer in YAA aged 15–24 years, diagnosed between 1995 and 2002 in the UK, was significantly lower than the European average.¹³

The major causes of death in 15–19-year-olds in the UK are shown in Fig 3.¹⁴ ‘External’ causes of mortality include traffic accidents, self-harm and violence. For the 15–24-year age group, and especially for young men in this group, these are the most important and potentially preventable causes of death in the UK.¹⁵

Fig 3: Deaths by cause and percentage of total among 15–19-year-olds in the UK, 2010.¹⁴



Morbidity

A huge burden of disease in YAA relates to mental health. Seventy-five per cent of all mental health disorders (excluding dementia) are present by 24 years of age, increasing in incidence from early adolescence onwards.⁶ Mental health problems are increased in young people with chronic disease, who may struggle with the developmental tasks of adolescence and young adulthood. YAA with chronic disease are more susceptible to problems with identity formation, a tendency towards depression and isolation, denial of illness and treatment, excessive emotional dependence on parents, and low self-esteem.

Sexual and reproductive health is another great burden for all young people, including those with chronic disease. The 2013 figures for England show that 63% of chlamydia diagnoses, 56% of gonorrhoea diagnoses, 54% of diagnoses of genital warts and 42% of genital herpes diagnoses occurred in YAA aged 15–24 years.¹⁶

Hospital use

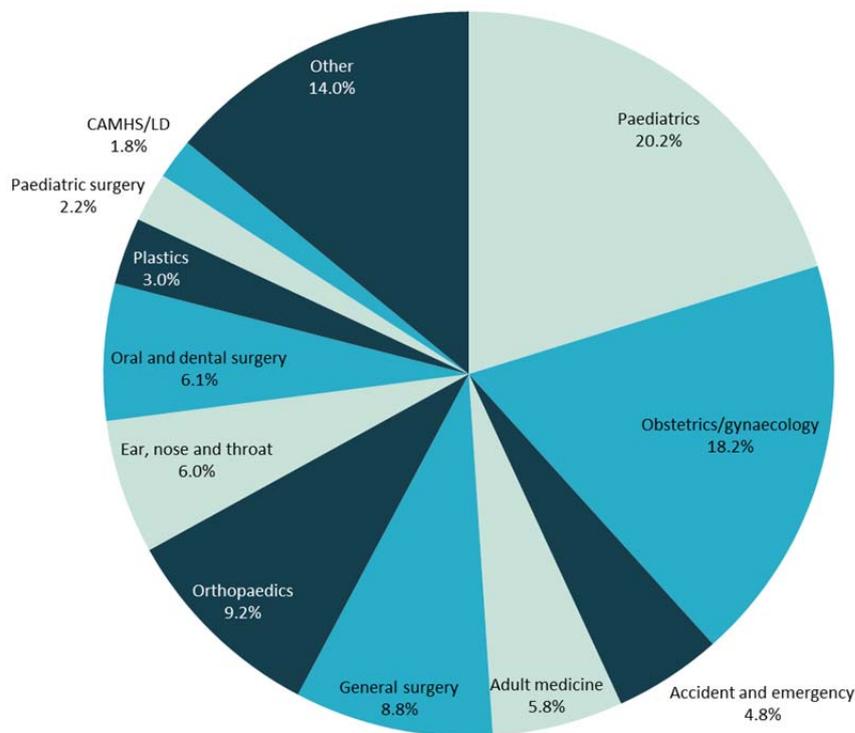
Inpatient activity

A recent review of Hospital Episode Statistics data for 10–19-year-olds in England shows that inpatient activity has increased faster for adolescents than for younger children over the past decade. As adolescents are admitted across a range of specialties, all physicians, except those exclusively involved in care of older people, have a role to play in their management.¹⁷

Children under 16 years who have medical problems are usually, but not always, managed in ‘paediatric’ services, and those 18 years and over in ‘adult’ services; 16- and 17-year-olds may be managed in either, with no consistency across services, and sometimes even ‘end of the bed’ arguments over which service is responsible for the care of a YAA.

Obtaining consistent information about reasons for medical admissions among 16–25-year-olds is a real challenge that contributes to and perpetuates the ‘invisible’ status of this population group.

Fig 4: Adolescent (10–19 years) inpatient activity by admitting specialty, England, 2010/2011.¹⁷
(CAMHS=child and adolescent mental health services, LD=learning disability)



Emergency care

The number of emergency presentations of 15–25-year-olds in 2012/2013 was 14.9% of total attendances, a slightly higher proportion than the presentations of 0–9-year-olds (14.4%).¹⁸ In England, emergency department attendances have increased by 31.7% over the past decade and now account for nearly 20% of inpatient care for 10–19-year-olds.¹⁷ YAA with chronic disease have a greater incidence of unplanned admissions than younger children or older adults with the same condition. Inappropriate attendances are elevated between the mid-teens and mid-20s, followed by a steady fall as age increases thereafter.¹⁹ An [RCP toolkit](#) offers advice on acute and emergency care for YAA.

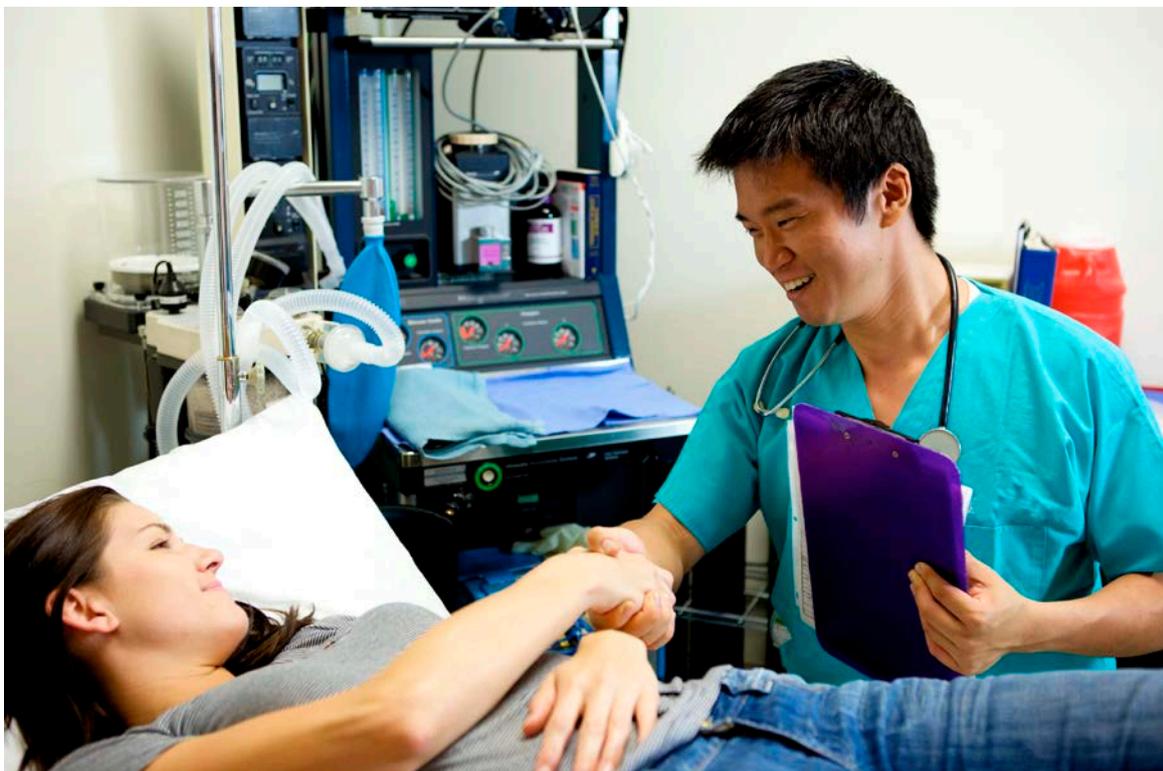
Primary care

Primary care is one of the few services that provide care over a person's lifespan. A London-based study of adolescent attendance at an urgent care centre (UCC), where attendees were triaged either towards a general practice (GP) service or to an A&E service, found that adolescents aged 15–19 years had higher rates of attendance at UCCs than at general practices. Young men and women aged 15–19 years were significantly more likely to visit the centres for their healthcare needs than to visit their GPs, both in normal GP hours and out of hours. This suggests that the UCC walk-in model of care suited this group better than making an appointment to see their GP (or perhaps that they do not have a relationship with a GP).²⁰

Satisfaction

The data demonstrate clearly that YAA already make up a significant proportion of the adult health service workload, but how do YAA feel about the care that they receive? Although most young people aged 16–24 years report a positive experience of NHS care, the patient satisfaction rate is lower for this age group than for older adults with respect to inpatient experience, primary care, perceived involvement in care, confidence and trust in their doctor, and being treated with respect and dignity.²¹ These differences reflect unacceptable gaps in the quality of care accessed by young people.

Young people are less satisfied than older adults with their inpatient experience, primary care, perception of involvement in care, confidence and trust in their doctor, and treatment as regards respect and dignity.²¹



3 Healthcare transition

What is healthcare transition and why does it matter?

Healthcare transition is ‘the purposeful, planned movement of YAA with chronic physical and medical conditions from child-centred to adult-oriented health-care systems’.²² Put simply, this means supporting a YAA as they move from a paediatric health setting (ie care by health professionals and in health settings dealing with all medical problems from birth to 16–18 years, depending on the service) to ‘adult’ care (ie care by health professionals and in health settings dealing with all medical problems in people over somewhere between 16–18 years of age and death). In reality, transition is much more than this. Physical health does not exist in isolation. Mental health, social relationships, lifestyle behaviours, family context and education are critical, particularly during this phase of life.²³ Therefore, transition must look beyond the purely medical aspects to be ‘the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of YAA as they grow up learning to live with their lifelong health condition’.²⁴

All YAA aged 16–25 years undergo multiple transitions that have a profound influence on their future health and wellbeing. Medical services must be designed to respond accordingly. Examples of the transitions that they may be dealing with include:

- attaining educational goals
- leaving the family home for higher education
- changes in family circumstances and dynamics
- starting employment
- establishing lifelong patterns of health behaviour related to substance misuse, diet, smoking and sexual behaviour
- forming short-term then long-term intimate partnerships
- starting their own family.

Having an illness during these formative years may have a huge influence on the life choices made by YAA. Opportunities to flourish and the potential to contribute to society may depend quite critically on how well the health service meets their needs. To complicate matters, at precisely the age of the transitions outlined above, secondary and tertiary care health services are largely divided structurally, functionally and philosophically into ‘paediatric’ and ‘adult’ services.

See Box 1 for an illustration of a young person experiencing multiple life transitions while also requiring healthcare services.

Box 1: A YAA with a chronic condition moving away from home.

Consider a 20-year-old male with type 1 diabetes, living away from home having just started at university. This young man does not have the maturity or experience needed to manage his disease by himself when there are so many other new things going on in his life.

What might happen to this young man in his new location?

- He must find a GP, then wake up at 8am to be the first on the phone to make an appointment.
- He must know how to get his primary care record transferred to the new GP.
- Transition might have enabled him to provide a three-sentence summary of his condition.
- He should have a clinical summary from his old team.
- He hopes there is a diabetic service for young adults, but instead finds himself in a diabetic service surrounded by older people with blindness and amputations.
- He needs to have all his prescriptions and equipment needs met, or he will run out of medication. Perhaps one day he looks 'unusual' to his friends, who take him to A&E where he is diagnosed with diabetic ketoacidosis (DKA).
- He is admitted to a medical assessment unit for management of the DKA. He is seen by a team with no training in the health needs of young people, in a four-bed ward shared with two older people with dementia and one seriously ill patient who dies overnight.
- Distraught, he contacts his mother who arrives for his discharge the next morning, bringing supplies of equipment. He decides to take more notice of the need to manage his disease.
- He is unsettled by his experience and, at the same time, is dealing with loneliness, missing home and stresses related to his personal life and course demands. He doesn't know how to find help with these issues, and he is trying to appear 'normal' to his friends.
- Working around his disease, he gets on with his social life (which involves irregular hours and meals, as well as use of alcohol and drugs) and with his intimate life (which may involve issues with sexual identity, contraception, sexually transmitted infections or break-ups).
- He manages to keep up with his chosen academic course, but worries about whether he'll ever get a job.

If you were his physician, would you be aware of all of these aspects of his life and how they impact his disease management? The system is simply not designed to meet his needs.

This young man is fortunate in many ways. He is in higher education and has the support of family and friends. It is a huge challenge for him, and will be very much more difficult for vulnerable YAA who are adversely affected by social determinants of health, such as income inequality, restricted access to education or employment, or lack of safe and supportive families.²³

After transition (if transition happens)

Only about half of young people who have childhood chronic disease have had any preparation for their transfer of care from paediatric to 'adult' medical services.³ Adolescence and young adulthood is also a time of onset of a number of relatively common chronic diseases, including inflammatory diseases, type 1 diabetes, some cancers and some neurological conditions. Young people who are diagnosed with these conditions will usually go straight into the 'adult' system without any support.

There is clear and accumulating evidence that brain development continues until about the mid-20s, particularly in the areas of judgement, reasoning and impulse control.²⁵ In comparison with early and mid-adolescence, late adolescence and early adulthood bring greater capacity for thinking about future consequences and regulating emotions, modulating risk-taking and making decisions about the future, including choices about health, relationships, education and careers. YAA can also weigh the impact of their choices on others more effectively than younger adolescents. Nevertheless, acquisition of these new skills does not mean that emerging adults are accomplished at executing them; NHS services should recognise and allow for this.

The health system is extraordinarily complex for even the most accomplished, articulate and mature adult to navigate, let alone a YAA. This age group may need to see a number of different specialists in different care settings and may have to travel considerable distances at considerable expense to access the care that they need. The transfer of healthcare from paediatric services often occurs at the same time as the loss of support from social services (eg disability living allowances, educational support, and adaption of a school to meet an individual's needs) as well as the major life transitions outlined above.

For an emerging young adult, support from friends, peers and colleagues may be valued just as highly as that from family members. Some may strive for independence from their parents. Friends are not traditionally taken into consideration in the management of chronic conditions in young adults and this can leave the YAA facing difficult decisions alone or continuing to depend on their parents.

4 What are the main challenges and barriers to good YAA healthcare?

Training in relation to YAA

Most doctors, nurses, allied health professionals, mental health professionals and others have been trained to specialise in either child or adult care. Training in the care of YAA exists but is little utilised.²⁶ The lack of trained professionals is a systemic barrier to delivering healthcare for the YAA population. Primary care, mental healthcare, multidisciplinary care, and the integration and coordination of health and social care are all critically important for many young people, especially those who have complex disease affecting a number of systems. Training must help healthcare professionals to get out of structural, age group- and disease-specific silos and bunkers in order to provide services that YAA can respond to. Greater flexibility has been called for to allow for continuity of care into early adulthood and a 'cadre of professionals who are trained in both paediatrics and the care of young adults, putting the young person at the centre and addressing the needs of 16- to 25-year-olds'.²⁷

In 2014, a survey of trainee physicians was carried out to assess the current state of higher specialist training in adolescent and YAA health across all medical specialties in the UK. Of those who responded, 70% rated training in adolescent and YAA health as 'minimal or non-existent'. The lack of training to deal with YAA issues was identified as the most significant barrier to delivering good adolescent healthcare by 74% of respondents.²⁸

YAA who have chronic or congenital conditions that were previously fatal during childhood, such as congenital heart disease or cystic fibrosis, increasingly survive well into adult life. These YAA need good-quality care provided by specialist teams who have disease-specific specialist expertise in relation to 'grown-up' childhood diseases. For some conditions, such as 'grown-up congenital heart'²⁹ and 'grown-up congenital or childhood onset liver disease',³⁰ training, networks and guidance are in place to provide this expertise. Healthcare professionals who look after YAA with chronic illness should also be cognisant of the additional healthcare needs of this age group. These include interaction of the particular condition or treatment with the management of mental and/or reproductive health issues (eg drug interactions, risks of pregnancy, or risk of passing on a disease). Services for young people should be aligned to provide ready access for all health needs.

Some chronic grown-up conditions in YAA coming into adult care are life-limiting. Palliative care for individuals who have these conditions must not be forgotten.³¹

The qualities that YAA rate highest in their healthcare professionals are honesty, attention to and treatment of pain, expertise, respect for patients, willingness to listen to concerns, and willingness to

share decision-making.³² Yet healthcare professionals are not supported in their ongoing training to meet the unique and legitimate expectations and needs of this population.

Support for physicians dealing with 'difficult' YAA problems

Lack of training in YAA issues that relate to transition can mean that both paediatricians and adult physicians find it a challenge when faced with YAA who are experiencing problems. Avoidance or feelings of helplessness can result, with poor outcomes highly likely for both patient and physician. Some conditions can be particularly challenging if training and support, particularly from already stretched mental health services, are not available. Such conditions include, for example, deliberate self-harm, medically unexplained physical symptoms, eating disorders and complex disability.³³

A survey of RCP members and fellows carried out in April 2015 found that many had experienced barriers to engaging with young people and their parents. Limited clinic time and lack of understanding of community resources were significant barriers to effective working with YAA.

Provision of services for YAA

There are many examples of excellent YAA healthcare. Sexual health services, teenage cancer services and many local centres of excellence provide good examples of meeting the healthcare needs of YAA in a developmentally appropriate way without the imposition of age barriers. There are important pockets of good practice in several medical specialties. There, joined-up working and coordination of services (supported by creative commissioning) are provided by healthcare professionals who receive support, funding or rewards for their efforts. These examples have been largely driven by good leadership and individual commitment to the cause of YAA. Data on outcomes that are easier to identify (such as transplant rejection rates, readily measured markers of diabetic blood sugar control (HbA_{1c}) or cancer survival rates) have helped to make the case for service improvements in some conditions.

Nevertheless, these services are often challenged by project limitations or heavily reliant on charitable funding. For many YAA, no developmentally appropriate service is provided because they are cared for and counted as though they were an adult.

For YAA with complex disability, the situation can be particularly poor. In paediatric services, coordination of their care is shared between hospital paediatric generalists and community paediatricians, with variable success. GPs are often not involved until the YAA becomes an adult at 18 years old. The GP then becomes the healthcare coordinator at a time when specialist services supporting the YAA, the family or carer, and the GP simply cease to exist or are drastically reduced because adult inpatient services are not equipped to meet all of the needs of this group. Affected

services include physical and mental health services, therapies, equipment provision, respite care, social support and educational services.

Limited evidence base for specific YAA services

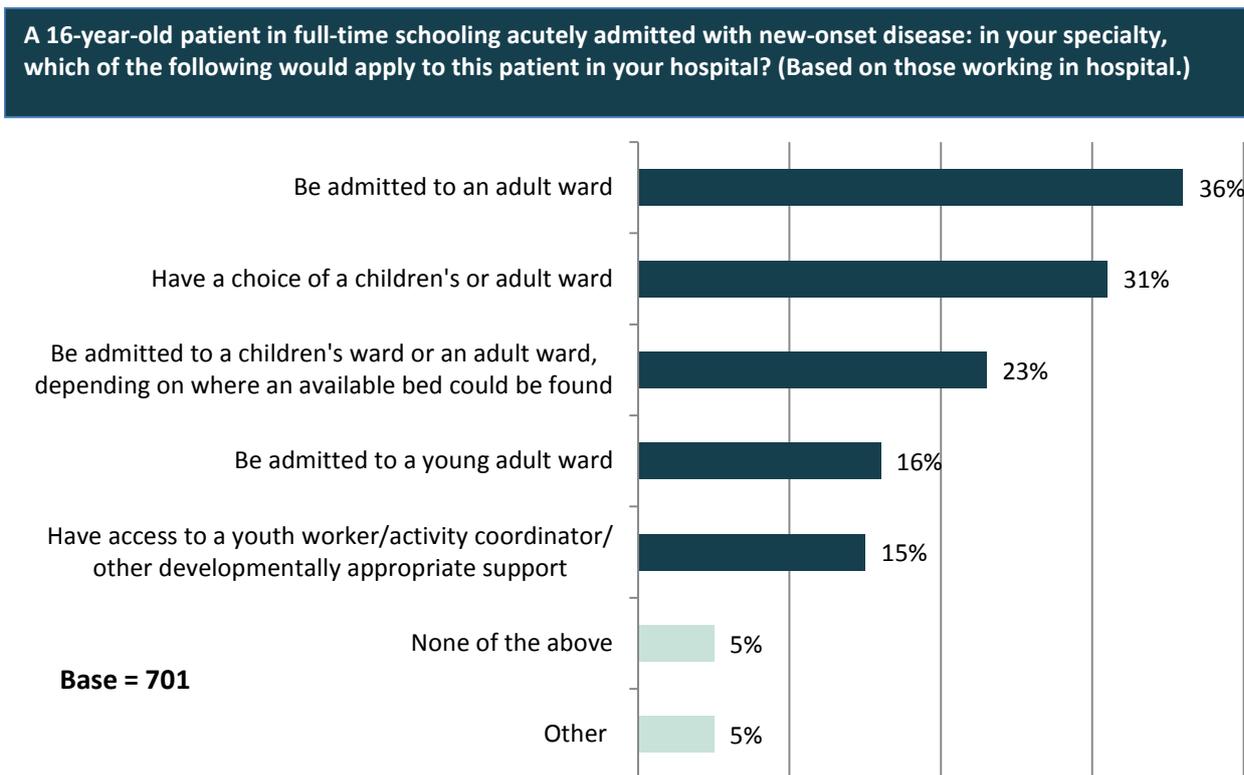
Higher-quality research is required in this area, in terms of both user satisfaction and health outcomes in relation to services for YAA. At present, the evidence base for any particular YAA service is limited.

Inpatient services

In general, YAA often have little choice about whether their inpatient care takes place in paediatric or adult wards, although some services (such as those for teenagers and young adults with cancer) are excellent and well designed.^{34,35} There is evidence that dedicated adolescent inpatient wards improve aspects of quality of care for young people aged 15–17 years compared with child or adult wards.³⁶ This means that larger hospitals should look to establish such dedicated units.

A recent survey of RCP members and fellows demonstrates the relatively limited choices for 16-year-olds in the UK. Just over a third of RCP members working in a UK hospital suggest that a 16-year-old person with new-onset disease would be admitted to an adult ward. Three in ten indicate that they would have a choice of a children’s or an adult ward (Fig 5).

Fig 5: Admittance options for YAAs.



YAA outpatient clinics

In a recent systematic review of transition, three out of four studies showed that running a clinic specifically for young adults in the adult setting was beneficial. Such clinics provide YAA with an opportunity for contact with peers and for individuals to settle into the new environment.³⁷

Projects that are based on specific conditions have shown positive results and have generated learning points that are applicable to other chronic diseases. For example, in 2010, NHS Kidney Care commissioned six project groups to develop innovative approaches for supporting YAA with kidney disease. The projects showed that significantly improved outcomes can be achieved by redesigning services to focus on people's needs and preferences, with only modest costs. Getting services right for YAA offers them the best opportunities for quality of life and the future.⁹

Being creative, using technology

Many small trials have shown that appropriate use of home-based technology can lead to improved outcomes and reduced admission to hospital. This in turn can improve the quality of life and deliver savings to the health and social care system. Yet implementation of these advances in England has been slow, and work remains focused on the care of older adults.³⁸ YAA clinics in various specialties have created their own websites and Facebook pages.³⁹ These can increase engagement and are an efficient, young-person-friendly means of communicating health-related information, support and social news. It should be noted, however, that many social media sites are not regulated, so the reliability of the health information that they can provide is questionable. Other models of care involve taking healthcare into a novel setting as a means of meeting more than one of the YAA agendas (Boxes 2 and 3).

Box 2: Providing young adult diabetes support via Skype.

Transitional and young adult (TYA) diabetes service, Newham University Hospital, Barts Health, London. Funded by The Health Foundation.

Newham has one of the youngest populations in the UK, with 30% of the population aged under 20 years. In 2008/09, the 'did not attend' (DNA) rate for the transitional and young adult (TYA) diabetes service was between 37% and 50%. The dual impact of genetics and environmental factors in Newham has led to a higher than national prevalence of type 2 diabetes in young people.

Solution

The service works with any patient between the ages of 16 and 25 years who has diabetes in the borough, currently around 215 people. The service ran a project carrying out consultations via Skype. All patients between 16 and 25 years were offered online follow-up via Skype whenever clinical examination was not required. Patients were encouraged to contact the service via Skype in an attempt to improve engagement and self-management.

Service implications

The diabetes specialist nurse and consultant had 1,644 Skype appointments involving 104 patients during the first 2 years. Overall, DNA rate was 13% for scheduled appointments, a reduction from a baseline of 25%.

Clinical outcomes

Promising initial results showed that, of the patients who had more than two Skype appointments, the average HbA_{1c} reduction was 5 mmol/mol, suggesting increased use of medication as prescribed and improved self-management.

Patient feedback (gathered through focus groups, interviews and questionnaires) included the following significant comments:

- 'I don't think the consultant or the nurses actually realise, their whole attitude changes when they are in the consultation clinic, they have got the papers in front of them, they are fiddling with that, they are reading through it, but when they are on Skype, they just look straight at you and they talk at you.'
- 'Skype has helped to change my mind set in terms of management. There's no excuse for missing appointments now.'

Challenges

There is a lack of financial incentive for internet-based consultations: the service receives £101 plus market forces factor (MFF) for a face-to-face follow-up consultation, but only £26 for a non-face-to-face Skype-based consultation.

Box 3: Cardiac Adolescent and Transition Service.

Great Ormond Street Hospital for Children NHS Foundation Trust

Young people with a structural congenital heart condition had difficulty accessing the pre-established transition clinic at Great Ormond Street Hospital (GOSH), either because they were not referred or because they did not wish to travel to London. There was no pre-existing nursing service at GOSH at the time when the service commenced; furthermore, there was no other dedicated adolescent and transition clinical nurse specialist within paediatric congenital heart services anywhere in the UK at that time.

Solution

The specialist nursing service at GOSH was set up to provide inpatient and outpatient support for young people and their families, to improve the coordination of inpatient and outpatient services for young people, to develop a range of resources for young people and their families, and to build levels of awareness and understanding around adolescent care among staff. The service is led by a cardiac adolescent and transition clinical nurse specialist, but has no allocated budget. It is staffed by one full-time cardiac adolescent and transition clinical nurse specialist and one lead consultant cardiologist for transition. Each clinical area has a link nurse to provide a local champion for adolescent care and to facilitate communication of information to front-line staff.

A total of 900 young people from across a wide geographical area are known to the service. Nearly 800 young people are seen in the transition clinic each year. The service provides tiered levels of care so that each young person receives the most appropriate care for their needs.

Young people in the service have a yellow sticker on the front of their notes to highlight their involvement with the transition service; the information on the sticker includes the contact details for the clinical nurse specialist. Staff can easily identify young people and contact the clinical nurse specialist for support.

‘Rhythmic Beats’, a day-long transition information event, was established in collaboration with charities. The event includes a programme of talks and workshops, as well as a ‘market place’ where young people and their families can obtain information across a range of issues from health and lifestyle; drugs, alcohol and smoking; sexual health; and schools and careers advice.

Outcomes

The service improves patient-reported experience and outcome measures. Rhythmic Beats reduces transition worries for young people and parents, and increases understanding of cardiac and lifestyle issues.

Coordinators or navigators across services

There is evidence that the appointment of an individual with a role in supporting YAA, particularly those with a long-term condition who are undergoing transition, can be cost neutral, as the initiative reduces length of stay and readmission rates, and improves outcomes. As shown in Fig 5, a recent RCP survey found that only 15% of services had a coordinator. Coordinators need to be able to signpost and facilitate access to mental health and to sexual health promotion or public health services; they also need to ensure that the GP is closely involved.⁴⁰

Standards of care and quality indicators exist but do not have ‘teeth’

In England, the ‘You’re Welcome’ criteria⁴¹ (first published in 2005) are a high-level strategy, with an initial investment programme that was developed to be applicable to all services for YAA and validated for use across all inpatient settings⁴² (Table 1).

These standards are a useful tool for service planners, physicians and other clinical and non-clinical leaders who are involved in the care of YAA. However, more needs to be done to lead, monitor and evaluate the implementation of these criteria.

The standards highlighted the key aspects of good-quality care for adolescents, including the need for YAA to take responsibility for their health and wellbeing, the importance of patients’ ownership of their transition, and the value of well-coordinated care. Domains that were central to YAAs’ experience of adolescent-friendly care were those that reflected clinicians’ attitudes, such as respect and friendliness, the quality of clinical communication skills, and perceived medical competency. Other significant

findings related to YAAs’ need to be involved in their own healthcare, to the provision of guideline-driven care, and to health outcomes. Accessibility of services in an age-appropriate environment that provides continuity of care was also significant. These findings have been



further supported in a systematic review of YAAs’ perspectives on healthcare.⁴³

Table 1: You're Welcome – quality criteria for young people friendly services.⁴¹

Criterion	Description
Access	Outlines how to ensure that services are accessible to young people
Publicity	Highlights the importance of effective publicity in raising awareness of the services available and explaining the extent of confidentiality. Effective publicity enhances access
Confidentiality and consent	Addresses confidentiality, consent and safeguarding, and how these are implemented by staff and understood by service users. This theme supports, and is supported by, local safeguarding arrangements
Environment	Addresses the service provision, environment and atmosphere, with the aim of ensuring that they are young people friendly (at the same time as being welcoming to all service users, regardless of age). The 'environment' is taken to include the atmosphere created by physical arrangements, as well as staff attitudes and actions. The environment can contribute to ensuring confidentiality for service users
Staff training, skills, attitudes and values	Addresses the training, skills, attitudes and values that staff need to deliver young people friendly services and to ensure that the needs of young people are met
Joined-up working	Addresses some of the ways to ensure effective joined-up delivery
Involvement in monitoring and evaluation of patient experience	Addresses the importance of capturing of young people's involvement in service development, monitoring and evaluation
Health issues for young people	Addresses the health needs of young people as they go through the transition into adulthood. Includes issues affecting all young people and issues affecting those with specific long-term health needs

There is cause for some optimism in the recent inclusion of the CQC's inspection models, which explicitly include transition in both children's and adult health services in hospitals, in primary care and in the community.³ These scores are factored into the overall CQC rating. NHS England has also recognised the importance of transition by appointing both a national clinical director for children and a national clinical director for children, young people and transition to adulthood. In addition, a NICE transition guideline, which aims to improve the planning, delivery and experience of young people in their transition from children's to adult services, is in development and due for completion in 2016.⁴⁴

Implementation and monitoring of transition and health-service provision for YAA are complex and challenging. The successful adoption of a comprehensive transition policy will require clarity around which group(s) are responsible (from both a legislative and a financial perspective) for each component of the process. Until these challenges are met and barriers are overcome, there is a risk that the outcomes for YAA will continue to lag behind those for other age groups. This is unacceptable and inequitable. Urgent action is needed, as listed in the suggestions for improvements in clinical practice (please see pp 4–5) to recognise and respond to the needs of YAA.

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