Chapter 20
Children and younger adults

20.1 Introduction and purpose

Although the ban on age discrimination in the provision of services and the exercise of public functions in the *Equality Act 2010* applies only to adults aged 18 and over, the new public sector equality duty requires organisations delivering public services to promote age equality for people of all ages, including children and young people.

The published literature looks at a wider range of issues associated with equality for children and younger adults and locally the NHS is likely to have additional examples of younger people receiving less favourable treatment. Webb argues that children experience considerable discrimination in healthcare,[591] and he identifies examples of both direct discrimination (stereotyping, age-blindness, marginalisation etc) and indirect discrimination (linked with poverty, homelessness etc).

Although most of the material in this guide addresses the needs and wishes of older people where there is a clear body of evidence about the extent and impact of age discrimination, this chapter focuses on issues related to younger adults and children. Just as the sections on older people covers a wide range of ages from 50 to over 100, this section also brings together issues relevant to people at very different stages of the life journey as children, teenagers and young adults, and people of working age.

As with older people, the implementation of the law requires localities to understand what practices are age-appropriate or age-sensitive and what are harmful discrimination for over 18s and breaches of the equality duty for all ages, including for children. Age-sensitive services and facilities are not discrimination if they can be shown to meet the legal test of "*objective justification*" – so, for example, it may not be discriminatory to have services that are focused on meeting the needs of older pregnant women who may have some age-related needs that may not be effectively addressed in the usual care pathways in a local maternity service.

[591] *Discrimination against Children*, Webb E in *Arch Dis Child,* 89**:**804-808, 2004

20.2 What does good age-equal practice look like?

Good practice in age equality for children and younger adults has features common to that for all ages – these are set out in the three responsibilities within the new public sector equality duty – the elimination of discrimination (which applies to people 18 and over), the advancement of equality of opportunity and the fostering of good relations between age groups. See annex *Outline of key features of the Equality Act*.

The *United Nations Convention on the Rights of the Child*, which includes articles on health and welfare, provides the starting point in shaping services for children that end unfavourable treatment and promote equality of outcomes. The national strategy for children and young people's health published in 2009[592] is based on these principles and articles as is part of the cross-government programme *Every Child Matters*.

- When focusing specifically on the needs and wishes of children and young adults, Young Equals, a group of charities and children who are campaigning to stop age discrimination, has published *Making the Case*[593] which brings together a wide range of evidence of age discrimination against children and young people. Young Equals is calling for protection from age discrimination in the provision of services and exercise of public functions for children and for schools and children's homes to be covered by the age element of the public sector equality duty.

Some children report particular difficulties in accessing health services when a combination of factors make them more vulnerable. As part of the *Get ready for change!* project, CRAE published an investigation into the human rights concerns of children and young people in England[594]. The *What do they know report* (2008) highlights children's experiences of discrimination on a range of grounds, including age. The report explores the issues for lesbian, gay and bi-sexual children, young travellers and recent refugees. Although not "*combined discrimination*" as set out in the *Equality Act,* addressing these barriers to access is part of delivering an age-equal service.

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[592] *Healthy lives, brighter futures: The strategy for children and young people's health* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094400

[593] *Making the case*, Children's Rights Alliance for England (CRAE), 2009 www.crae.org.uk/protecting/age-discrimination.html

[594] *Get Ready for Geneva,* CRAE, 2008

20.3 Organisational framework

Leadership and motivation

The features of high quality leadership, especially clinical leadership, set out in Chapter 3 Leadership and motivation are equally relevant here. Recommendation 17 in *Achieving age equality in health and social care*[595] highlights the crucial role for leaders in bringing about the cultural change required to promote age equality in services for people of all ages. As part of the *Every Child Matters* programme, a resource book for leaders of children's services has been published[596] and the Royal College of Nursing[597] and the Royal College of Paediatrics and Child Health[598] support clinical leaders of children's services.

Joint working

Although the principles and rationale for providing 'joined-up' services are the same for all ages, the legal framework for partnership working between different sectors in children's services is based around the *Children's Act 2004*, which included a duty to cooperate on all statutory agencies in a locality providing services to children and young people. The Act created children's trusts which are the vehicles through which the agencies work together to provide joined-up services.

The precise cooperation arrangements underpinning children's trusts can vary between localities and may range from formal agreements with pooled budgets and delegated functions to sharing staff, buildings, equipment, knowledge and skills.[599] However there are a set of essential features common to all arrangements:

- a child-centred, outcome-led vision for all children and young people, clearly informed by their views and those of their families
- inter-agency governance, with robust arrangements for inter-agency cooperation
- integrated strategy: joint planning and commissioning, pooled budgets
- integrated processes: effective joint working sustained by a shared language and shared processes
- and integrated front-line delivery organised around the child, young person or family rather than professional boundaries or existing agencies.[600]

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[595] *Achieving age equality in health and social care*, Sir Ian Carruthers and Jan Ormondroyd, 2009
[596] *Every Child Matters*, Department for Children, Schools and Families (DCSF), 2006
www.dcsf.gov.uk/everychildmatters/strategy/managersandleaders/championingchildren/children/
[597] www.rcn.org.uk/development/communities/specialisms/children_and_young_people/forums/rcn_proessional_forums/clinical_leadership
[598] www.rcpch.ac.uk/Policy/Clinical-Management
[599] www.dcsf.gov.uk/everychildmatters/about/aims/childrenstrusts/childrenstrusts/
[600] www.dcsf.gov.uk/everychildmatters/about/aims/childrenstrusts/childrenstrusts/

Involvement of children and young adults

Article 12 of the *United Nations Convention of the Rights on the Child* sets out the right of children to say what they think should happen and have their opinions taken into account. Although Chapter 6 focuses on the involvement of older people in services, much of the general guidance on involvement is relevant to children and younger adults. There are many guides about enabling the involvement of children and young people – the following search in NHS Evidence will produce a range of documents [601] including the government publication *Learning to Listen: core principles for the involvement of children and young people*. The Department for Children, Schools and Families (DCSF) has brought together a range of material on the participation of children in developing and running children's trusts.[602]

Quality

The core standards of high quality services to children and young people were set out in the 2004 *National Service Framework for Children, Young People and Maternity Services*.[603] Policy proposals in *Healthy lives, brighter futures* are designed to 'cement' delivery of these standards.

One of the key quality criteria in relation to age equality is ensuring that services for children and young people are age sensitive. In 2007 the Department of Health published the *You're Welcome* quality criteria that help the NHS judge whether their services, facilities and information are friendly for young people under 20.[604]

Workforce

As part of delivering age-appropriate services, the need for specially trained and qualified staff to work with children and young people has been recognised for many years in the NHS and is now regarded as a crucial part of delivering a high quality service. Skills for Health have a range of resources to help NHS organisations have the "*right flexible, affordable workforce to meet the needs of the future provision of childcare*",[605] while the professional bodies have a huge range of supporting material (for example the Royal College of Nursing and the Royal College of Paediatrics and Child Health). NHS Employers also have a work programme to support the children's workforce[606] which is focused on supporting the Healthy Child Programme, the early intervention public health programme which begins in pregnancy and extends through childhood into the teenage years.

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[601] www.library.nhs.uk/PPI/SearchResults.aspx?catID=8789
[602] www.dcsf.gov.uk/everychildmatters/strategy/participation/participation/
[603] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089100
[604] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073586
[605] www.healthcareworkforce.nhs.uk/backup/childhealth.html
[606] www.nhsemployers.org/PlanningYourWorkforce/childrensworkforce/Pages/Children'sWorkforce.aspx

20.4 Specific services

Although there are specific studies that show where there is unfair treatment based on age for young adults and children, there are two main areas that are common across different services:

- Evidence of less favourable treatment for different age groups - Young Equals[607] concludes that "*research reveals a pattern of behaviour under which older children, usually (but not solely) aged 16 and 17, receive less favourable treatment from health services than adults or younger children, either due to a complete lack of services or to a lack of age-appropriate service provision*" (p8).
- **Improving the transition from children's to adult services** – in 2006 the Department of Health published *Transition: getting it right for young people,*[608] which focused on the needs of children with complex long-term conditions that in the past would have caused death in infanthood. In 2008 this was followed by *Transition: moving on well*[609] that provided advice on supporting young people with complex health needs in the transition process. It stressed that transition needs to be managed by paediatric staff working with colleagues who provide services for adults and the importance of multi-agency working, and provided an example of a 'health transition plan' that could help the process.

Primary and community services

In 2004 the Department of Health published guidance for primary care professionals about their role in delivering the *National Service Framework for Children, Young People and Maternity Services*.[610] The Department of Health has recently published guidance on community-based services for children and young people, including school health services [611] This is part of the Transforming Community Services programme which focuses on improving both quality and productivity.

The concerns raised by Young Equals about health services for adolescents were also looked at by Ann McPherson[612] who concluded "*the specific health needs of young people are often neglected by primary care as it is believed that adolescents are on the whole a healthy group who rarely present to their general practitioner (GP). 'Out of sight' has been 'out of mind', especially given the ever increasing*

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[607] Young Equals, CRAE, 2009
[608] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145
[609] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592
[610] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089113
[611] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101425
[612] British Medical Journal, 330:465-467 (26 February), doi:10.1136/bmj.330.7489.465, 2005

pressures on primary care from other client groups." McPherson uses the conclusions of qualitative research into the views and wishes of young people to identify actions that primary care could take to improve communication, access (such as temporary registration) and general friendliness.

Cancer services

Delivering age-appropriate cancer services for children and young people is a crucial part of the drive to improve cancer services. The National Institute for Clinical Excellence has produced guidance called *Improving the outcomes with children and young people with cancer*[613] which recommends some key features of a high quality cancer service.[614] These include ensuring that services are age-appropriate and that a register of people aged 15 to 24 with cancer should be considered.

In 2009 the National Cancer Action Team highlighted the new standards for children's cancer services that have been incorporated into the *Cancer Manual*.[615]

The Teenage Cancer Trust, a charity that supports teenagers and young adults with cancer, estimated that 50 per cent of teenagers with cancer are not treated in age-appropriate facilities and highlighted that children aged 16–18 have often been unable to access community and palliative care facilities because children's support ends at 16 and adult support begins at 18.[616]

Diabetes

The need to deliver high quality services to children and young people has been recognised as an important component of local diabetes services. *The National Service Framework for Diabetes* had two standards relating to children and young people: Standard 5 related to high quality services and Standard 6 stated that:

> *"All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people's clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them."* [617]

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[613] *Improving the outcomes with children and young people with cancer* , National Institute for Clinical Excellence, NICE, 2005
[614] http://guidance.nice.org.uk/CSGCYP
[615] www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_108667
[616] *Making the Case,* Young Equals, 2009
[617] *The National Service Framework for Diabetes,* Department of Health, 2001 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002951

Diabetes UK has published a case study of good practice from Dartford, Kent which runs specific 'transitional clinics' for adolescents.[618]

Research has shown that even after transition, there are still issues in the care that young adults with diabetes receive. Gray et al[619] looked at Quality and Outcomes Framework data in practices in South London and concluded that *"there are large variations in diabetes management between general practitioner practices, with care seemingly worse for younger adults".* Despite the cholesterol and glycaemia (though not hypertension) recordings showing greater need, younger adults (i.e. 18 to 44) had lower recorded levels of interventions to manage the diabetes compared to the older age group.[620]

Children with disabilities

In 2007 the Departments of Health and Children and Family Services launched a transformation programme for services for disabled children.[621] The programme supports local delivery of the standard in the National Service Framework which covers services for children with disabilities that aims to promote social inclusion as well as high quality care.

However campaigning organisations continue to raise concerns that the rights of children with disabilities are not always met. Every Disabled Child Matters (EDCM) is a campaign to get rights and justice for every disabled child and in 2009 it published a report which highlighted a range of problems with access to both general and specialist health services for disabled children and greater transparency in the funding of services for children with disabilities.[622]

"Aiming High for Disabled Children" highlighted the importance of transition support and so DH and DCSF have together launched the Transition Support Programme which covers the range of services that work with disabled children.[623] There is a range of material on managing the transition for specific conditions, such as complex neurological conditions,[624] renal disease,[625] cystic fibrosis[626] etc.

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[618] www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Children_and_Young_People/Childrens-Diabetes-Services-in-Dartford/
[619] *Association of age, sex and deprivation with quality indicators for diabetes: population-based cross sectional survey in primary care*, Gray J et al, Journal of Royal Society of Medicine 99: 576-581, 2006
[620] *Association of age, sex and deprivation with quality indicators for diabetes: population-based cross sectional survey in primary care*, Gray J et al, Journal of Royal Society of Medicine 99: 576-581, 2006
[621] *Aiming High for Disabled Children,* Department of Health, 2007
www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC/
[622] www.ncb.org.uk/edcm/campaigns/health.aspx
[623] www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/transition/transition/
[624] www.acnr.co.uk/JF09/ACNRJF09_young_people.pdf
[625] www.springerlink.com/content/tbgkauqv61fne662
[626] www.cftrust.org.uk/aboutcf/cfcare/transition/

The Care Quality Commission[627] reviewed the work on "*transition planning*" led by local authorities and concluded that while some localities had made progress, the overall position is that the work is underdeveloped. Only 40 per cent of councils said that they were developing transition-specific training for their own staff or with other professionals, while only 68% reported having joint arrangements and multi-agency protocols in place for transition.

In 2010 the Department of Health published the National Framework for Children and Young People's Continuing Care,[628] which parallels the guidance for adults. It sets out a process for agreeing bespoke packages of continuing care for those children and young people under the age of 18 who have ongoing care needs that cannot be met by existing services alone.

Mental health

Just as there has often been a traditional separation between working age adult and older people's mental health services, there has been an age-based separation between Child and Adolescent Mental Health Services (CAMHS) and services for working-age adults. These age-based differences are not in themselves examples of discrimination – there are reasons for organising services so they are sensitive and appropriate to the different needs of people at different ages. However commissioners and providers need to be active so that the age-based structure of services is not a contributory factor leading to the less favourable treatment of some individuals and groups on the basis of their age. An example is the national decision that both adult and CAMHS services are covered by the 18-week waiting time target.[629]

The need to actively manage the transition between CAMHS and adult mental health services has been recognised for several years. In 2000 the Health Select Committee highlighted problems with a gap between some CAMHS only accepting children under 16 years old and some adult services only accepting adults over 18.[630] The National CAMHS Review reported in 2008[631] and set out the features of a high quality CAMHS service which they defined as supporting children and young people up to the age of 18. Singh et al[632] suggest several service options that localities could consider to ensure services meet the needs of young people linking between CAMHS and adult services, including specialist services for 16-25-year-olds, liaison services, joint working, specialist workers astride the service and protocols and guidelines.[633]

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[627] *State of health care and adult social care in England,* 2009 www.cqc.org.uk/stateofcare.cfm
[628] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784
[629] *Improving access to child and adolescent mental health services*, Department of Health and Department for Children, Schools and Families, 2009
[630] www.parliament.the-stationery- office.com/pa/cm199900/cmselect/cmhealth/373/37312.htm
[631] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090399
[632] *Mind the gap: the interface between child and adult mental health services*, Singh S et al, The Psychiatrist, 29:292-294, 2005 http://pb.rcpsych.org./cgi/content/full/29/8/292
[633] *Mind the gap: the interface between child and adult mental health services*, Singh S et al, 2005

The National CAMHS Review also set out how local services should support individual young people in the transition from CAMHS to adult services. The Department of Health has issued guidance to the NHS on managing the transition across all services, including mental health,[634] which recommends that professionals work with children with complex needs and their families to produce a "*health transition plan*".

In 2007 the Royal College of Nursing also published advice on managing transition called *Lost in transition: moving young people between child and adult services*.[635] A recent report by the National Foundation for Educational Research highlights the specific issues for children leaving care.[636]

Sexual health

In 2010 the Department of Health published the first national strategy for sexual health and HIV[637] and in January 2010 an Equality Impact Assessment (EqIA) for the national sexual health policy. This highlighted the inequalities in the sexual health of young people, citing the relatively high number of unintended pregnancies and sexually-transmitted infections (STIs), with the exception of HIV. The 2005 *Standards for Sexual Health Services*[638] describe the elements of a comprehensive sexual health service but for young people the key linkages between reducing teenage pregnancies (which is the focus of a cross-government Public Service Agreement) and reducing STIs are crucial. The EqIA says "*there is some evidence to suggest that an increased focus on behaviour change could help reduce inequalities*".[639]

Traditionally the access point to sexual health services was through GPs but over the past few years it has been recognised that young people are more likely to access services through other routes. For example *Healthy lives, brighter futures* stresses the need for accessible sexual health advice and highlights the work done in partnership with further and higher education and the online and telephone advice service *RUthinking*.[640]

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[634] *Transition: moving on well*, 2008 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592)
[635] www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227.pdf
[636] *Provision of mental health services for care leavers: transition to adult services*, Lamont E et al, 2009 www.nfer.ac.uk/nfer/publications/LAT01/LAT01_home.cfm?publicationID=321&title=Provision%20of%20mental%20health%20services%20for%20care%20leavers:%20transition%20to%20adult%20services
[637] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111227
[638] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4106273
[639] *Equality Impact Assessment,* p6, Department of Health, 2010
[640] *RUthinking*, Department of Health, 2009

The National Chlamydia Screening Programme[641] screens men and women under 25, who are sexually active, through a range of local access points. The evidence shows that rates of infection are lower in people over 25 but they can be tested following discussions with their GP or local sexual health services.

Maternity services for young mothers

The need for age-appropriate services for young mothers has been highlighted and, as a result of commitments made in *Teenage Parents Next Steps*, the Department for Health (DH), Department for Children, Schools and Families (DCSF) and the Royal College of Midwives published a revision of *Teenage parents: who cares - a guide to commissioning and delivering maternity services for young parents* in 2008 aimed at commissioners of maternity services and heads of midwifery in the NHS.[642]

DH and DCSF also jointly published *Getting Maternity Services Right for Pregnant Teenagers and Young Fathers*[643] which is aimed particularly at practitioners working in areas where the prevalence of teenage births is relatively low and there may be no dedicated services for pregnant teenagers.[644]

Both publications explained the reasons why immediate antenatal referral for pregnant teenagers by midwives is so important. They also recommended to their different audiences that maternity services develop care pathways specifically for teenagers and that they incorporate these referrals as a matter of routine practice.

Urgent and emergency care (including ambulance services)

As part of the drive to improve urgent and emergency care services over the past decade, there has been a focus on the emergency care pathway for children, especially related to developing age-appropriate services, such as dedicated areas in accident and emergency (A&E) departments. The Royal College of Paediatrics and Child Health provides emergency and urgent care pathway advice to ensure services are effective and age appropriate.[645]

One of the main concerns raised by children about emergency services is that sometimes ambulance services will not take calls from children. CRAE.[646] gives examples of children being told that they need to find an adult to make the emergency call.

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[641] www.chlamydiascreening.nhs.uk
[642] http://publications.dcsf.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=DCSF-00414-2008
[643] *Getting Maternity Services Right for Pregnant Teenagers and Young Fathers*, Department of Health and DCSF, published in 2008, revised 2009
[644] http://publications.everychildmatters.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=DCSF-00673-2009
[645] www.rcpch.ac.uk/Policy/Emergency-Care
[646] *We are all equal and that's the truth! Children and young people talk about age discrimination and equality*, Children's Rights Alliance for England, 2007

Fertility

The impact of the *Equality Act* on access to certain infertility services has been recognised by the Expert Group on Commissioning NHS Infertility Provision which said:

> *"A survey carried out by the Department of Health early in 2009 reports that the number of primary care trusts (PCTs) providing three cycles of IVF has increased from 5 per cent to nearly 30 per cent. Nearly 50 per cent are providing two or three cycles, with 25 per cent providing one full cycle and 22 per cent one fresh cycle. This is welcome progress, but there continues to be a need for a reduction in the number of PCTs providing only one cycle of IVF, particularly as PCTs need to bear in mind the provisions of the Equality Bill and to provide services accordingly*."[647]

The key guidance was produced by the National Institute for Health and Clinical Excellence and the Royal College of Obstetricians and Gynaecologists[648] and recommended the following:

> *Women should be informed that the chance of a live birth following in vitro fertilisation treatment varies with female age and that the optimal female age range for in vitro fertilisation treatment is 23–39 years. Chances of a live birth per treatment cycle are:*
>
> - *greater than 20% for women aged 23–35 years*
> - *15% for women aged 36–38 years*
> - *10% for women aged 39 years*
> - *6% for women aged 40 years or older.*
>
> *The effectiveness of in vitro fertilisation treatment in women younger than 23 years is uncertain because very few women in this age range have in vitro fertilisation treatment.*

The Department of Health's position is summarised in section 3.6 of the *Regulated fertility services: a commissioning aid:* [649]

> *3.6.1 Though strongly encouraged, adherence to NICE's clinical guidelines is not mandatory. Recognising that immediate implementation of the guideline on infertility would pose problems for the NHS, the then Health Secretary John Reid advised the NHS by means of Chief Executive Bulletin 207 (20–27 February 2004) that:*

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[647] Expert Group on Commissioning NHS Infertility Provision, Department of Health, 2010 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111363

[648] www.nice.org.uk/cg011

[649] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101070

- *the Department would be looking to primary care trusts (PCTs) who provide no IVF treatment to meet a minimum national level of provision of one cycle of IVF by April 2005; and*
- *in the longer term he would expect the NHS to make progress to full implementation.*

3.6.2 In August 2008, Dawn Primarolo, the then Public Health Minister, wrote to PCTs and specialised commissioning groups. In her letter, she said that NICE was planning a review of its clinical guideline in 2010/11, but advised that commissioners should not delay implementing the guideline in the belief that it was about to be superseded. She also reiterated that references in the NICE clinical guideline to cycles of IVF should be interpreted as meaning full cycles, which are ones in which suitable fresh embryos are transferred and remaining suitable embryos are frozen, stored and subsequently transferred if required.