

*This vision does not represent government policy but provides useful insight into how services for children & young people with cancer might develop over the next 5 years*

## **Annex M**

### **Children & Young People (CYP) with Cancer 2012**

#### **Background**

- 1) Around 1,500 children are diagnosed with cancer each year in the UK and there are around 250 deaths – cancer is now the commonest cause of death in children ahead of accidents.
- 2) Around 1,600 teenagers and young adults (13-24 year olds) are diagnosed with cancer each year in England and Wales and there are around 300 deaths from cancer in this group. There are particular challenges for this group because of the lack of age-appropriate facilities uniformly across the country.

#### **Key Priority**

- 3) The key action required is the full implementation of the recommendations in the NICE guidance on *‘Improving Outcomes for Children & Young People with Cancer’* across the NHS in England by 2010. A programme of national peer review visits should be completed by 2012 to confirm whether the IOG has been fully implemented and, if not, what actions are outstanding and when and how they will be addressed.
- 4) For children with cancer, implementation of this IOG will need to include:
  - a) some reconfiguration of services to ensure that principal treatment centres (PTCs) have sufficient caseload and staff to deliver optimal care – this is likely to require a reduction in PTCs. The location of these PTCs should be determined by the specialist commissioning groups in consultation with stakeholders;
  - b) support from local shared care services delivered in line with the 3 levels agreed by this group – strong links (with defined care plans) between PTCs and shared care services will be vital with PTCs keeping overall responsibility for CYP with cancer.
- 5) For teenagers and young adults (TYA) with cancer, it is estimated that 70% are not treated in a setting appropriate for their age. Implementation of the CYP IOG will therefore require provision of a sufficient number of dedicated age-appropriate TYA services in PTCs to ensure that every network has a service to refer to – more than one service may be needed in high density populations.
- 6) For both groups, implementation of this IOG will require:
  - a) commissioning of services across the patient pathway;
  - b) improved co-ordination both between PTCs and shared care and for the transition between child, TYA and adult services;

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- c) increased workforce in line with the IOG so that all CYP have their care supervised by multidisciplinary teams with training and experience in the care this group. This will require:
  - i) robust workforce plans across the whole pathway of care taking into account medical and psycho-social needs;
  - ii) increases in posts and improved recruitment into areas where there are currently shortages such as medical (eg. paediatric haematology), nursing (eg. clinical nurse specialists), and psycho-social support;
  - iii) more investment in training so that services are staffed by people with knowledge and expertise in managing this group and are familiar with discussing the needs of CYP at the time of diagnosis and taking into account their views;
  - iv) a balance of paediatric and adult trained staff for TYA;
  - v) greater clarity about the role of the lead nurse for CYP with cancer;
  - vi) greater recognition of the importance of AHP support to the care of CYP and increased investment in these services

## **Other Priorities**

### *Increasing Awareness of Signs & Symptoms of Cancer*

- 7) By 2012 both professional and patient/parent awareness of the signs and symptoms of cancer should have improved leading to less CYP having delayed cancer diagnoses.

#### Raising awareness among professionals

- a) NICE has updated referral guidelines for suspected cancer which includes a section on children and young people. However, cancer in children and young people is rare and the group is divided on whether or not it is realistic to have a dedicated training programme on the signs and symptoms of cancer in CYP. There is agreement that there is evidence of some delays by professionals in picking up possible cancers particularly in TYAs. For example:
  - i) of over 200 TYAs at a recent conference, 47% had visited their GP with symptoms 4 or more times before being referred to a specialist;
  - ii) some cancer types in CYP seem more susceptible to delayed diagnosis, in particular bone sarcomas, brain tumours and lymphoma.

By 2012 it is suggested that:

- graduate & post graduate medical education should include modules on cancer in CYP including the cardinal signs that should trigger early referral to an appropriate PTCs;
- there should be a defined set of tools and referral criteria to support GPs, practice nurses and any other health professionals who come into

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- contact with CYP (including in hospital) to recognise possible cancer so it can be diagnosed with minimum delay;
- it should be easier for patients (including CYP and their families) to get an alternative opinion if they are dissatisfied with a decision made in primary or secondary care.

#### Raising awareness among CYP/Parents

- b) delay in seeking medical advice is less common in children because parents are generally quick to recognise if their child is unwell or something is not “normal”. Delays are more common among TYAs - over half of the 200 TYAs at a recent conference were not really aware that TYAs got cancer. By 2012 we should be:
  - i) empowering TYAs to challenge health professionals if they have concerns about their health and ensuring that GPs understand that many young people only visit their doctor when they have serious concerns;
  - ii) improving health education in schools, colleges, universities and with major employers of young people so that the signs and symptoms of possible cancer are understood along with when and how to access help and advice;
  - iii) running periodic public awareness campaigns on the signs & symptoms of cancer including those relevant to CYP.

#### *More local services*

- 8) Although the case for centralising the specialist services that CYP with cancer need in principal treatment centres is strong there are some services that could and should be provided more locally both in (formally designated) shared care units in local hospitals (see para 5b) and through community nursing support with links to these units.
- 9) Anecdotally, we understand that children’s community nursing teams are being reduced or withdrawn in some communities. They may be seen as a “soft” target when financial savings are needed. By 2012 the important role of community nursing teams in caring for and supporting CYP with cancer and their families needs to have been accepted and action taken to strengthen rather than weaken their local presence and enhance their links with the shared care services and principal treatment centres. Action should also have been taken to ensure that these staff have received the necessary training for managing CYP with cancer and that their competencies are maintained.

#### *Support during treatment*

- 10) Both children and young people with cancer have specific needs that will need to be taken into account when planning to develop services. The majority of these should be addressed with full implementation of the CYP IOG (eg. key workers,

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multidisciplinary needs assessments and comprehensive networks of care & support services). In addition to these, by 2012 there should be:

- a) Consistent guidance for schools and universities on how to manage educational needs of pupils with long-term conditions (incl. cancer) who cannot be in school/university for long or repeated periods.
- b) improved educational & other support from schools/colleges/ universities:
  - i) for CYP being treated for cancer – about a years education can be missed on average and better support and co-ordination with schools and colleges would minimise the impact of this;
  - ii) for students returning to school following treatment – this may be particularly important for CYP who have been treated for a brain/central nervous system tumour or who have had cranial radiation;
  - iii) for those of 17 years plus approaching university entrance or who have already embarked on college/university courses.
- c) efforts to ensure CYP are not discriminated against because of their condition. For example, a national ID card scheme is proposed for TYA with cancer to minimise discrimination by the hospitality industry in relation to dress codes which, as a result of treatment, a young person cannot always comply with. Over 80% of TYAs attending a recent conference wanted to have such a card.

### *Palliative care*

11) By 2012 we should have:

- a) adopted an integrated care pathway for palliative care for all children and young people which includes both voluntary and statutory services;
- b) developed and implemented, in partnership with child and adult services, local models of palliative care delivery which are tailored to the needs of CYP with cancer. In developing these models it will be important to consider:
  - i) smaller palliative care day units at a local level;
  - ii) night care to support CYP in their own homes;
  - iii) more services relevant to diverse and multi-cultural communities;
  - iv) better communication around transitions between child, TYA and adult services;
  - v) less reliance on voluntary sector funding;
  - vi) bereavement support as and when required by families.

### *Survivorship*

12) Children and young people with cancer have a better chance of survival now than 20-30 years ago. About 1 in 1000 adults is a survivor of childhood cancer and there are more than 15,000 survivors in the UK. This number is set to rise. However, many treatments that CYP with cancer receive have long term side effects some of which may not become apparent until years after treatment has finished. It is estimated that 60% of survivors have one or more treatment/disease

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related side effect that will need medical management. We need to manage this better.

- 13) By 2012 there should be more measures (developed nationally and rolled out) to support survivors of cancer including:
- a) strategies/models for long term follow-up which start in childhood, manage the transition into young adulthood and on into adulthood and address the training needs of healthcare professionals;
  - b) a mechanism for identifying late effects of cancer treatment and ensuring early intervention for these at an individual patient level but also at an aggregated level so patterns/trends can be established and warnings given/action taken where appropriate, such as happened with the Hodgkin's recall exercise in 2003;
  - c) more research into late effects of treatment in CYP surviving cancer;
  - d) better and more timely information and support about fertility ie. risk of any infertility, fertility preservation methods, risk of cancer in future offspring. This should be provided by appropriately trained staff. There should also be clarity about funding responsibilities for fertility preservation and therapy.

#### *Transition*

- 14) Turning from a child to a young person to an adult can be a difficult time for the person involved with physical and emotional issues to deal with. Health services are generally divided into child and adult services but the transition between the two is important. By 2012 this transition should be being managed better with a seamless journey for the patient between child, TYA and adult services which takes into account their personal needs and preferences.

#### *Information*

- 15) By 2012 there should be access to better information (developed at a national level and rolled out) including:
- a) information prescriptions in a format specifically designed for CYP with cancer (as part of the information prescription project);
  - b) user experience surveys for defined age groups that consider the specific needs of children, young people and their parents and address issues such as the experience of a young adult treated in an adult environment vs a dedicated teenage facility;
  - c) clinical outcomes (including quality of life not just survival)– professional groups need to determine the dataset needed to provide more sensitive outcome measures and its collection should be mandatory. Data might need to carry a health warning as the numbers of CYP with cancer are small and the conditions diverse;
  - d) pooled international experience/information;
  - e) improved knowledge derived from registration of cancer in TYAs co-ordinated at network and national level.

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### *Commissioning & Cost of Services*

- 16) It is important that we strengthen commissioning of cancer services for CYP. By 2012, well informed commissioners, using high quality information on service standards and clinical outcomes, should be commissioning optimal care across the whole patient pathway – diagnosis, treatment and supportive & palliative care – for all CYP who develop cancer. Development of a CYP commissioning guide by the end of 2007 would help.
- 17) It is hard to imagine increasing quality of services without increasing costs although it is noted that there may be more cost effective ways of organising services which could provide some savings for re-investment. What will be key is that by 2012:
- a) the PbR system should reward quality not just activity and how this will be done needs to be clear to all stakeholders;
  - b) all perversities from the PbR system should have been removed, eg:
    - i) tariffs that are disincentives to providing certain services (eg. for young adults) or act as a disincentive to reducing length of stay;
    - ii) managing ‘over-stays’ ie. there needs to be allowance for contingencies to accommodate varied demand for less predictable care pathways.

Unless action is taken there is a risk of good teams being disaggregated in the short term to save money as CYP cancer services generally lose money under the existing tariff/PbR system.

### *Clinical Trials*

- 18) The majority of children have the opportunity to participate in clinical trials and this should continue. However, the situation is less impressive for TYA. Over 70% attendees at a recent conference reported that they were not offered the chance to be treated in clinical trials. By 2012:
- a) clinical trials for cancers occurring in CYP should contain eligibility criteria that reflect the specific cancer biology including its age incidence pattern;
  - b) all CYP with cancer should be treated in centres where a complete portfolio of relevant trials is supported. These clinical trials should be developed through co-operation between clinical researchers from both children’s and adult oncology;
  - c) action should already have been taken to lessen the bureaucracy that currently surrounds research activity and is already stifling research.

### *Support for Parents*

- 19) Support for parents of CYP who are ill (including with cancer) needs to be improved. It is important to recognise that centralising services will have implications for families in terms of travel, parking, over-night accommodation, support and disruption to family/work life. Parents need to be able to care for their

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children (including young people) when they are unwell and they should have a full package of workplace rights including time off from work as well as existing measures such as the right to ask for flexible working patterns.

20) By 2012 DH should have taken the following actions to support parents with CYP who are ill (including with cancer):

- a) made provision for assistance with travel and hospital parking costs for families where CYP have prolonged hospital admissions, and increased awareness and take up of the Hospital Travel Costs Scheme,
- b) ensured that adequate levels of accommodation are provided for resident parents;
- c) collaborated with other government departments to produce guidelines for parents and employers to establish a comprehensive set of rights in terms of time off, paid leave, carers policies, flexible working when CYP are ill;
- d) collaborated with other government departments to consider introducing a statutory entitlement to paid leave from work, as is available in some other European countries;
- e) ensured mechanisms are in place to provide parents, siblings and peers with support after bereavement.

**Children & Young People with Cancer IOG Advisory Group  
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