

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 and young people with cancer 2015

Background

1. Around 1200 children (0-15 yrs) and 1600 (16-24yrs) teenagers and young adults are diagnosed with cancer each year in the UK¹. Approximately 250 children (0-14 yrs) and 320 teenagers and young adults (15-24 yrs) died from cancer in 2009². Cancer is now the most common cause of death in children ahead of accidents.
2. Preliminary estimates indicate that, on a UK population basis, the number of life years gained, or at stake, in patients diagnosed with cancer at age under 24 years ranks second, behind breast cancer.
3. The review of services for children and young people (CYP) undertaken by Professor Sir Ian Kennedy (DH 2010) should be reflected in the continuing development of services for CYP with cancer.

Key priorities

4. The key priorities for services for children and young people with cancer for the coming years to 2015 are that:
 - **there is compliance with Improving Outcomes Guidance (IOG)**
 - **there is access to safe local services**
 - **young people are treated in age appropriate care settings**
 - **early diagnosis initiatives also address CYP & awareness of signs & symptoms is increased**
 - **CYP survivorship issues are appropriately addressed**
 - **the workforce increases in line with the IOG**
 - **there are improvements in chemotherapy services**
 - **there is reduced variation in paediatric oncology neurosurgery services**
 - **the impact of proton beam therapy treatment on paediatric services is effectively managed and**
 - **training and education for those caring for CYP is addressed.**
5. The following sections address each key priority in turn and go on to set out the other priorities identified for CYP with cancer services.

Improving Outcomes Guidance compliance

6. 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. It is the responsibility of local commissioners to work with their clinical networks to ensure that the IOG is fully implemented. Ministers have given a clear steer that the IOGs are clinically evidenced, outcome focused, and implementation will continue to be monitored. Peer review of children and young people's services will be undertaken 2011/12. The role and remit of the NHS in extending cancer peer review beyond NHS services to include those third sector organisations providing CYP cancer services will be considered.

¹ Cancer Registrations England 2008 - Office for National Statistics (ONS).

² Mortality Statistics deaths registered in 2009: Table 5 Deaths¹ underlying cause, sex and age group in 2009 summary - Office for National Statistics (ONS).

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7. For children with cancer, the challenge in the coming years will be for Principal Treatment Centres (PTCs) to remain IOG compliant while specialised services commissioners ensure a sustainable national network of PTCs. This may require a re-assessment of how many IOG compliant PTCs are sustainable. Specialised Commissioning Groups (SCGs) have identified thirteen Children's PTCs, and thirteen linked TYA PTCs. This work will be linked to that undertaken as part of the 'safe and sustainable' review of specialised children's services such as paediatric neurosurgery and cardiology.

Access to safe local services for all

8. Children and families will have access to safe and local cancer service for some components of care in hospital or in the home. This will be set up to agreed pathways to ensure all arrangements are clinically safe, sustainable and affordable. Every local children's unit providing shared care to children with cancer needs to have suitably trained staff and be formally linked into the children cancer network-coordinating group with agreed clinical guidelines and governance arrangements with a PTC. The maintenance of such local arrangements is fundamental to the provision of care closer to home. Such shared care services are particularly vulnerable to some of the proposed changes to the commissioning of services, and local commissioning will have a key role to play across the pathway of care from the home to the tertiary centre.
9. Community children's nursing teams (CCNTs) should be linked to the PTC and will provide cancer-specific care in conjunction with, and supported by a team of Paediatric Oncology Outreach Nurse Specialists covering the PTCs' catchment area. There are examples in some part of the country where children with cancer are excluded from receiving input from generic CCNTs, when children with other 'specialist' conditions are afforded this service from the team. Children with cancer have care needs that can, and should be, met by generic community teams and this same service should be developed for older teenagers and young adults.

By 2015:

- the important role of community nursing teams in caring for and supporting CYP with cancer and their families will have been accepted and action taken to strengthen rather than weaken their local presence in line with the recommendations in 'Transforming Community Services' and enhance their links with the shared care services and principal treatment centres,
 - action will have been taken to ensure that these staff receive the necessary training for managing CYP with cancer and that their competencies are maintained.
10. The recommendations of the CLIC Sargent report: '*More than my illness*' and recommended model of care outside hospital will have been piloted and evaluated. This will require Children Cancer Networks (PTC, shared care units and community services) to look for opportunities to test and evaluate components of the model in their practice settings, and disseminate the findings to encourage other services to adopt new service models where these have proved to improve outcomes and/ or patient experience.

Appropriate Care Settings for young people

11. In 2007, it was estimated that 70% of TYA patients were not treated in a setting appropriate for their age. Full implementation of the CYPIOG will therefore require sustainable provision

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of age-appropriate TYA services in PTCs, and agreed referral pathways for each tumour group. This will ensure that every cancer network has a TYA service.

12. To improve outcomes and improve patient experience for TYAs the key challenges are:
 - mandating referral of all new and relapsed TYA cases aged 16-24 yrs inclusive to a TYA MDT for case review and age-appropriate cancer pathway planning,
 - embedding the role of TYA MDT in cancer services and enhancing collaborative decision-making and work with site-specific MDTs,
 - developing models of shared care for TYA patients to provide safe and age-appropriate care in a formal relationship with a highly specialised TYA PTC with TYA MDTs,
 - ensuring all patients under 19 are referred to a TYA PTC for treatment and that all 19-24 yr olds have fully unhindered access to treatment at a PTC. NCAT and NHS choices are providing a web-based information resource to help young adults decide upon their preferred cancer care setting, www.nhs.uk/youngcancercare. This aligns with the new patient choice and shared decision-making agenda, and provides a model for other cancer patient groups.

Early Diagnosis & Increasing Awareness of Signs and Symptoms of Cancer

13. While work needs to be done specifically to raise awareness of signs and symptoms of cancer for CYP, it will also be important to ensure that national work aimed at ensuring the earlier diagnosis of cancer patients addresses children and young people. Delays in diagnosis cause distress to young people and their families and may affect survival.
14. By 2015, both professional and patient/parent awareness of the signs and symptoms of cancer should have improved leading to fewer CYP having delayed cancer diagnoses. There should be data recording systems in place to ensure that this is evaluated.
15. **Raising awareness among professionals:** NICE has updated referral guidelines for suspected cancer that 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.

By 2015:

- graduate and post graduate medical education should include modules on cancer in CYP including the cardinal signs that should trigger early referral to an appropriate PTC,
 - we should work towards defining a set of tools to support awareness of referral criteria among GPs, practice nurses and any other health professionals who come into contact with CYP (including in hospital) to recognise possible cancers and to follow appropriate pathways to rapid diagnosis, focussing on primary and secondary care,
 - 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,
 - education should include '*working with and understanding young people with cancer and their families*'.
16. **Raising awareness among CYP/Parents:** 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. At two recent conferences, only 20-30% of TYA reported delaying beyond 4 weeks and of those 60% had

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felt that their problems could not be serious or were reassured by parents, other relatives or friends. The majority of patients sought help rapidly but only 20 - 30% were referred rapidly and the remainder (70 - 80%) had to go back to their GP repeatedly (40% went 4 - 5 times before referral).

17. National Awareness and Early Diagnosis Initiative programmes that relate to the cancer awareness of children and young people in the population will be encouraged, as will the programmes provided by the third sector in educational establishments. Robust evaluation and impact assessment of such programmes will be necessary to provide evidence of effectiveness to support national rollout, so all young people can receive education about cancer.

By 2015:

- TYAs should have sufficient information to feel empowered 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,
- health education will be improved 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,
- there will be periodic public awareness campaigns on the signs and symptoms of cancer including those relevant to CYP.

Survivorship

18. Children and young people with cancer have a better chance of survival now than 20-30 years ago. About one in 1,000 adults is a survivor of childhood cancer and there are more than 26,000 survivors of cancer experienced as a child or young person 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. We estimate that 60% of survivors have one or more treatment/disease related side effects that will need medical management. We need to manage this and the social, emotional and educational impact of a cancer diagnosis better to improve the quality of life for CYP and their families.
19. There needs to be nationally coordinated, focused research into the late effects of cancer and its treatments in addition to access to appropriate clinical trials that are specific to young people. These will have a positive impact on the identification, prevention and management of any adverse long-term consequences of survival.
20. By 2015:
 - there will be 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 or action taken where appropriate,
 - there will be better and more timely information pertaining to the late effects of cancer and its therapies. In particular there will be enhanced support for resultant problems with fertility, sex and relationships more generally; this will include the risk of any sub-fertility, fertility preservation methods, risk of cancer in future offspring; information should be provided by appropriately trained staff,
 - there will be clarity about funding responsibilities for fertility preservation and therapy which will be made available where appropriate to all young people starting cancer treatment,

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- work on CYP survivorship initiative test sites will be completed and evaluation of data on new models of follow up care published; the successful models will be rolled out to more centres and CYP survivorship evidence will be embedded into measures for PTC late effects MDT,
- work will be undertaken on commissioning of risk-stratified pathways for follow up and late effects,
- there will be more research on the management of late effects,
- alternative models of follow up and use of remote access/ technology will be in place so that every hospital follow up visit undertaken will deliver added value that cannot be achieved by other means less costly to the NHS and the patient/ family.
- survivors of brain tumours are a particularly vulnerable group, the provision of facilities for this population in adulthood needs to be reviewed and improved.

Workforce

21. The workforce will need to increase 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 within the PTC, shared care arrangements and local community teams. This will require:
- robust workforce plans across the whole pathway of care taking into account medical and psycho-social needs,
 - increases in posts and improved recruitment and retention in areas where there are currently shortages such as medical (eg. paediatric haematology, nursing (eg. clinical nurse specialists), and psycho-social support,
 - 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,
 - support is provided for clinicians to develop international trials,
 - greater clarity about the role of the lead nurse for CYP with cancer,
 - greater recognition of the importance of AHP support to the care of CYP and increased investment in these services,
 - CYP need a professional lead in each GP practice with a specialist interest in this age group to move services forward,
 - GPs and commissioning consortia are supported by good links with PTCs for CYP cancer so they can seek advice as required,
 - GPs need to be involved with the CYP and their family throughout the entire pathway so that they can provide support in the community, this is particularly relevant at the end of treatment,
 - investing in professionals who will provide psychological support for CYP throughout their treatment is of paramount importance
 - significant investment will require corresponding tariffs to reward best practice,
 - there will be nationally agreed nursing and medical staff competencies in TYA cancer care, agreed minimum training levels for ward staff, and the training programmes to deliver this.
22. There is a need to link CYP nursing developments with those in other cancer services to establish the impact of the role of nursing on improving outcomes and experience. For example, see *Nursing Contribution to Cancer Care* - DH 2010, there are savings and quality improvements to be made by specialist nurses:
- coordinating more personalised services differently and more locally, (in the community and at home),

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- making better use of local CYP health and social care services, as well as other local services such as education and youth services,
- utilising primary care services better, through better assessment, needs-led care provision,
- developing CNS key worker role as specialist cancer advisor to generic children and young people's services,
- for TYA particularly, linking into local employment, education and training (EET) agencies more proactively to maintain developmental progress and social integration during cancer.

Chemotherapy

23. The key recommendations of NCAG will be reflected in children's and young people's cancer service chemotherapy measures for PTCs and shared care services. In the future the Quality Standards for Chemotherapy will apply across children's, TYA and adult services.
24. The underpinning principles of the Acute Oncology Service will be incorporated in children's shared care arrangements, including minimal level shared care agreements, where children may be initially assessed and stabilised but then transferred to a PTC for ongoing management. Services for TYAs will need to be detailed in local arrangements for the Acute Oncology Services, whether they are under the care of a PTC, or local services.
25. The NHS Cancer Drugs Fund should refer to drugs for children and young people.

Paediatric oncology neurosurgery

26. The IOG indicated the variation in paediatric neurosurgical centres in terms of volumes and sub-specialist expertise in brain tumours in children. This work is being addressed in the 'safe and sustainable' specialist children's services programme of the NSCG. This may affect the current pathways for neuro-surgical management of children with brain tumours and robust arrangements should be established between centres to provide coordinated care for patients and families.

Radiotherapy - Proton beam therapy

27. With the establishment of Proton Beam Therapy Services in England, and the recommended paediatric service adjacencies, there will be an impact on existing paediatric services. Work is to be undertaken to revise the current assumptions and pathways for paediatric cancer patients so that, where surgery and chemotherapy are also required, the most appropriate care can continue to be delivered locally wherever possible. There will need to be nationally agreed pathways for referral and treatment and robust arrangements for the provision of coordinated care for paediatric patients and their families.

Training and Education

28. Professor Sir Ian Kennedy (DH 2010) has recently highlighted the fundamental importance of training for those engaged in the care of children and young people:
 - more investment is required in multi-professional 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,
 - the RCN CYPCN group has recently developed some specific competencies for nurses caring for children and young people with cancer, and work should be done on specific competencies for TYA,

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- a national approach is needed to the provision of education to those engaged in the speciality.

Other priorities

Maintaining the profile of CYP cancer services

29. The profile of CYP and CYP related activity will need to be maintained throughout the National Cancer Programme. The cancer equalities agenda for CYP should be embedded at the highest level at DH and in the NHS. CYP services should be considered for every cancer programme work-stream established. When a decision is made not to include work for CYP services within the cancer programme an explicit explanation should be provided. For example, when CYP cancer care is adequately covered by a DH CYP policy team initiative, there needs to be clarity between policy teams where the responsibility for including CYP cancer services lies, and where joint programmes will be initiated. The coordination and synergy between Cancer and CYP policy development and delivery that has been achieved by the relevant national directors jointly leading the CYPIOG advisory group will be continued.

Patient Choice

30. Work has been undertaken to provide Patient Choice for TYA aged 19-24 years of age in response to the recommendation in the IOG that services that care for young adults aged 19 – 24 years provide that young person with a choice, where possible, as to where they would like to receive this treatment. This could be in a PTC, with comprehensive age appropriate cancer facilities, or an adult Cancer Hospital with an appropriate site-specific service, which may be nearer home, linked to a PTC through the TYA MDT.

31. By 2015:

- every young person aged 19 - 24 yrs, with a cancer diagnosis, will have knowledge about the website and will have been given the opportunity to choose their place of care and will have an understanding on how this may impact on their care.
- cancer professionals will be aware of this website and how practice should be implemented locally; they should also be aware of the requirement for young people to make a choice and will ensure that unbiased choice has been offered.

Support during treatment including non-health/clinical care areas, such as guidance for schools and universities

32. Both children and young people with cancer have specific needs for consideration when developing services. The majority of these will be addressed with full implementation of the CYP IOG (e.g. key workers, multidisciplinary needs assessments and comprehensive networks of care & support services). In addition, health and education agencies should work more collaboratively. Learning mentors employed in some centres have successfully supported TYAs through their cancer treatment and have provided the vital link between schools/ university/ college and vocational placements.

By 2015:

- there will be consistent guidance for schools and universities on how to manage the educational needs of pupils with long-term conditions (including cancer) who cannot be in school/university for long or repeated periods,
- the potential benefits of establishing specific posts to support employment, education and training for young people will be better understood. The charities currently funding

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these posts will be encouraged to further explore and evaluate these roles and potential funding streams with education authorities,

- there will be improved educational and other support from schools/colleges/ universities.

Support for Parents carers and siblings

33. Support for parents of CYP who are ill 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 and work life. Parents need to be able to care for their children and 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.

34. By 2015:

- there will be 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,
- there will be adequate levels of accommodation provided for resident parents, and partners/carers of young people,
- there will be guidelines for patients, parents and employers regarding their rights in terms of time off, paid leave, carers policies, flexible working and benefits entitlement when CYP are ill, produced in collaboration with other government departments,
- we will have considered introducing a statutory entitlement to paid leave from work, as is available in some other European countries in collaboration with other government departments,
- there will be mechanisms in place to provide parents, partners, siblings and peers with support during cancer treatment and after bereavement.

Transition

35. 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. At present, there is a discrepancy between the cut off age for different elements of the service, for example, there are in-patient units that take patients up to 16 years of age and community teams that accept referrals up to 19 years. Transitional care for young people with long-term conditions such as cancer involves educating and supporting the individual to achieve a developmentally appropriate role in relation to managing their health care needs, the consequences of cancer and its treatment and achieving an adult role in society. Delivering individualised, planned and managed transfer of care between age-defined healthcare services is an important component of this transition for young people with cancer.

36. By 2015:

- there will be better communication around transitions between child, TYA and adult services. In particular, there will be clarity around provision of palliative and end of life care for patients aged 17-18 years who may fall between paediatric and Adult Services,
- transition should be managed better with a seamless journey for the patient with 'continuity of care that ignores birthdays and concentrates on need'. (Kennedy report 2010),
- transition will be a planned and organised process with the involvement of the paediatric, TYA and adult teams, and may take place over a period of several months or years,

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- there will be strategies and models for long term follow up that start in childhood, manage the transition into young adulthood and on into adulthood and address the training needs of healthcare professionals.

Palliative and End Of Life Care

37. By 2015:

- an integrated care pathway for palliative and End of Life Care for all children and young people which includes both voluntary and statutory services will have been adopted,
- the service provision gap for TYAs aged between 16 - 18yrs will be closed,
- local models of palliative care delivery which are tailored to the needs of CYP with cancer developed and implemented, will have been developed in partnership with child and adult services,
- Links will be established to ensure national work on CYP palliative care will benefit CYP with cancer,
- there will be improved links between adult specialist palliative care and TYA PTC's outreach services to meet needs of young adults with cancer, with better use of adult plans to deliver palliative care for TYAs.

Information

38. **For patients & their families:** there should be access to better information for children, young people and families developed at a national level and rolled out.

By 2015:

- information prescriptions will be in a format specifically designed for CYP with cancer as part of the information prescription project,
- CYP information pathways will have been developed.

39. **On services outcomes and user experience:** there is a need to develop specific tools to elicit the experiences of children, as well as surveys of TYA, and of parents' experiences. Children, young people and parents should be included as a matter of routine whenever the national cancer patient experience survey is undertaken.

40. 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. Data included needs to address clinical outcomes as well as treatment given.

By 2015, there will be:

- clinical outcomes data including quality of life (not just survival),
- international data available to benchmark services,
- improved knowledge derived from registration of cancer in TYAs co-ordinated at network and national level,
- national user experience surveys for defined age groups that consider the specific needs of children, young people and their parents.

Commissioning and Cost of Services

41. It is important that we strengthen commissioning of cancer services for CYP. Cancer in children and young people is always a rare event, and commissioning will need to be undertaken at the specialist level. Well informed commissioners, using high quality information on service standards and clinical outcomes, should be commissioning optimal

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care across the whole patient pathway from diagnosis to treatment, supportive care, including psycho-social and educational / employment support, and palliative care, whether in the PTC or in local care, for all CYP who develop cancer. Critical to this will be an interface and dialogue between specialist and local commissioners to ensure both appropriate specialist acute provision and access to relevant generalist local community services, particularly in both the survivorship phase and during end of life care for those who do not survive.

42. The costs of providing CYPIOG compliant services in TYA PTCs are not included within adult cancer tariff prices. As there are no separate HRGs for TYA activity these episodes are not separately identifiable from general adult cancer activity, and tariff prices are as for general adult cancer activity. Tariff prices need to reflect the complexity of CYP care and the potential long-term benefits of this care. This should be addressed as the data become available. The system should have sufficient incentives for shared and other local care services to be developed.
43. By 2015:
 - maximum use will be made of levers in existing and emerging systems that reward quality not just activity, including the use of best practice tariffs,
 - guidance for commissioners of CYP services should highlight all incentives that they may be able to use,
 - the Cancer Commissioning Toolkit and Guidance will have new sections on commissioning for CYP,
 - Commissioning for Children and TYA specialised (PTC) services will be the responsibility of the NHS Commissioning Board which will enable the move towards a more unified approach, to align service models and provision,
 - the work on paediatric chemotherapy regimen tariffs to ensure any organisation delivering chemotherapy is adequately reimbursed and to clarify which HRGs should be applied to POSCU activity will be complete,
 - bundles of risk-stratified personalised continuing aftercare will be commissioned to comprehensively support those at risk of, or living with, the consequences of young people's cancer.

Clinical Trials and Health Services Research

44. The National Cancer Research Institute's TYA Clinical Studies Group has benchmarked clinical trial accrual for TYA across England. For commonly presenting tumour types, 50% of children enter trials and only 20% of TYA. Better information should be made available to TYAs and it should be a priority for discussion at the TYA MDT.
45. There is a pressing need to support health service research that explores the outcome, experience and cost differential of TYA MDT involvement and or TYA PTC based care. More broadly, it should also explore the models of shared care in CYP services that were recommended by the CYPIOG, including a need to better understand the benefits of TYA PTC care compared to non PTC care for the 19 -24 year olds.
46. By 2015:
 - clinical trials for cancers occurring in CYP should contain eligibility criteria that reflect the specific cancer biology including its age incidence pattern,
 - 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,

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- action should have been taken to lessen the bureaucracy that currently surrounds research activity and stifles research,
- all CYP with malignancy to have the opportunity to have treatment within relevant clinical trails,
- there will be greater collaboration between centres to ensure that children in particularly rare disease groups, or where conventional treatments have failed, are offered entry into appropriate clinical trials,
- we will understand, in greater detail, the underlying biology of malignancy in children, teenagers and young adults,
- we will build on the knowledge gained from the development of new understanding and treatments to continue to improve care,
- there will be further collaboration and support for joint international trials, for example, for rare malignancies in this age group,
- there will be research activity to help us understand the outcome benefits to the NHS of specialised TYA cancer services,
- there will be increased research to further our understanding of the late consequences of survival from cancer experienced as a young person,
- there will be research activity to explore the outcome benefits of shared care across the age range.

**CYP IOG Advisory Group
December 2010**