

Implementing the CYP IOG

**NCIN Children Teenagers and Young Adults Clinical
Leads Workshop**

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National Cancer Action Team

What does the CYP IOG say?

“An appropriate balance of service provision and allocation of resource”
“Safe and effective services as locally as possible, not local services as safely as possible”

- Clear organisational structures, Network Leads
- Establish Principal Treatment Centres (PTCs) and referral pathways
- PTCs to provide sustainable range of services, defined staffing
- Shared care, with defined areas of responsibility agreed with PTC
- Care delivered by Multidisciplinary Teams
- All care under 19yrs in age-appropriate facilities, 19yrs and over must have unhindered access as required
- All patients must have access to tumour-specific expertise
- Access to clinical trials, or treatment on agreed protocols
- Registration of cancers in 15-24 year olds

CYP IOG Implementation - Structures

- CYPIOG Implementation Advisory Group

Joint National Director Chairs: Prof Mike Richards (cancer), Dr Sheila Shribman (children's)

Clinicians, commissioners, parent groups, cancer charities, DH, CAT

- CYPIOG Commissioners Group

Joint SCG Director Chairs: Sue McLellen (London), Cathy Edwards (Yorkshire and the Humber)

- National Working Groups and Project Groups to support implementation
- SCG and Cancer Network CYPIOG Implementation Groups at local level
- Children and Young People's Cancer Network coordinating group linked to SCG and Cancer Networks

Baseline Assessments

- Baseline assessments completed by January 2007

Providers

- CCLG, CCLG+TYA, 'Stand alone' TYA - To assess how their service compares with the IOG minimum infrastructure

Cancer Networks

- To gain a better understanding of :-
 - where patients are treated
 - what shared care arrangements are in place
 - the strengths/weaknesses of community services
 - where young people with cancer are currently treated

Baseline Assessment – Key Findings

- Wide variation in numbers of new patients treated at PTCs
- Inequalities in access to shared care
- Inequalities in teenage and young adult access to IOG-recommended services
 - 49% 16-18s
 - 10% of 19-24s
- Workforce gaps:
 - nursing
 - paediatric haematology
 - paediatric pathology
 - allied healthcare professionals

What does CYP IOG say about Shared Care ?

- For most patients it will be appropriate and necessary for some elements of care to be provided by their local hospital rather than PTC
- Commissioners should ensure that shared care arrangements are established which
 - identify a lead clinician and a lead nurse
 - have approved clinical protocols for treatment and care
 - define areas of responsibility with the PTC
- Defines core membership of multidisciplinary teams at non-PTC treatment sites
- Identifies core components of PTCs, MDTs and shared care arrangements

Core components of shared care arrangements

- Coordinated care supported by appropriate structures and processes
- Named lead consultants in PTC and at local level
- Identified nurse and pharmacist lead at local level
- Robust 2-way systems of communication
- Age appropriate environments
- Written guidelines to support the level of care agreed
- Education and training programmes for staff in all settings
- Arrangements for unexpected admissions
- Identified contacts for families
- Identified funding

Shared Care Working Group

- Established by CYPIOG Advisory group to look at:
 - Levels of shared care
 - Resources for shared care
 - Workforce issues
- National consultation on guidance and recommendations
- Produced:
 - Definitions of Levels of Care – shared care Level 1, 2, 3 + PTC
 - Recommendations for quality measures to support peer review (infrastructure document)
 - Clinical Governance agreement template
 - Information for Commissioners

TYA's – IOG Challenges

- CYPIOG crosses paediatric and adult service models
 - TYA requirements additionally cross disease site-specific teams
 - Implementation of adult site-specific IOGs already underway or completed.
 - Adult services have been peer reviewed for IOG compliance, prior to CYPIOG.
 - Services for young people need to comply with site-specific IOGs and CYP IOG.
 - Tension between further centralisation and provision of local care.
 - Potential perception that children's services 'sorted' and Young Adult services 'too difficult'
- Additional national leadership, direction and guidance was required to advise commissioners and providers on implementation.

TYA Guidance

- Paper to Advisory Group July 2007, highlighting gaps in IOG, outstanding issues and seeking direction to progress:
- Advisory Group agreed some basic principles:
 - All patients aged 16-24 yrs must be notified to a TYA MDT at a PTC (Young People) to ensure access to age-specific expertise.
 - Core services of PTC (Young People) should be defined, to provide access to tumour-specific expertise and age-appropriate facilities.
 - Patients aged 19yrs and over to be offered informed choice of treatment by TYA MDT at PTC or local adult MDT/cancer service.
- Advisory Group agreed that more detail was required to inform and support commissioning discussions and decision-making.
- Agreed to establish short life TYA Working Group to develop supplemental guidance, to be formally approved by Advisory group, for DH and CAT.

TYA services commissioning

- All 16-18 yrs inclusive to be treated at a PTC (young people)
- All 19-24 yrs inclusive to be offered referral for treatment at a PTC
- All 16-24 yrs inclusive must be discussed by a site-specific MDT **and** a TYA MDT
- Systems of referral/notification must not introduce delays
- There must be identified a lead medical clinician for each patient,
- Shared care not precluded in delivering CYPIOG-compliant services.
- All shared care arrangements must be a partnership with PTC, and agreed by commissioners.
- TYA MDT at PTC has care coordinating function across services
- Core facilities/services of a PTC may have to be in more than one hospital/Trust but must be within one city
- Robust arrangements for transition between age-defined services must be developed.

CYPIOG Progress – *and challenges*

- Baseline assessment verified and analysed for national picture
- Children's shared care guidance
- TYA service commissioning guidance, *new ways of working*
- TYA national cancer registry
- National 'map' of Children and Young People's Cancer Networks
- SCGs identified Principal Treatment Centres (PTCs) for children and for young people - *robust and sustainable for the future*
- Planned development/*introduction of shared care*
- Timescaled implementation plans agreed for all Cancer Networks
- *Investment plans to deliver IOG compliant services*
- Children's measures published

Next Steps

- Implementation of agreed plans for children's and TYA services
- TYA measures in development
- CLIC Sargent ' More than my illness' project – impact and testing?
- Young Adult's Cancer Choices project – NCAT and NHS Choices
- CYP Advanced Communication Skills training roll-out
- Paediatric chemo regimens into national list for PbR
- Ensuring cancer tariffs support service improvement
- Service pathways and specifications to support commissioning
- Electronic commissioning toolkit – CYP ?
- Performance/service outcome measures – whole pathway metrics
- Peer Review programme 10/11 children self-assessment, 11/12 external all CYP
- **Measuring impact of CYPIOG on clinical and patient outcomes, and the effectiveness of new service models – the Quality and Productivity Challenge!**