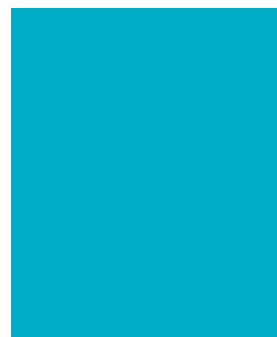
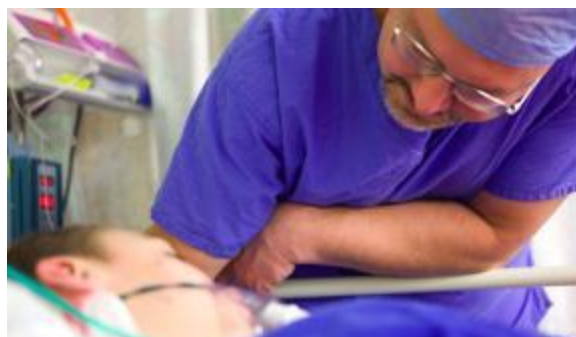


# NCIN CTYA Workshop: TYA CRG Priorities



Alison Cameron  
TYA CRG  
Chair of Metrics Sub Group



# What does NHS England commission?

- Specialised cancer services for 16 – 24 year olds in PTC and designated hospitals
  - ‘*The Manual*’ <http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf> defines the scope of prescribed specialised services – page 237
- “..Specialist cancer services for children and young people from Children’s PTCs and Teenage and Young Adult PTCs...[and] ..services delivered at about 90 shared care centres through the 26 PTCs. Specialist cancer services for children and young people include:
- All cancer chemotherapy and radiotherapy
  - Specialist palliative care services, survivorship, long-term follow up and specialist therapies and rehabilitation

# TYA CRG web page

<http://www.england.nhs.uk/resources/spec-comm-resources/npc-crg/group-b/b17/>

TYA CRG Chair - Rachael Hough			
<b>NORTH</b>		<b>MIDLANDS &amp; EAST</b>	
North East	Emma Lethbridge	West Midlands	David Hobin
Greater Manchester	Michael Leahy	East of England	Helen Hatcher
Yorkshire + Humber And Vice Chair	Dan Stark	East Midlands	Jo Poole
Cheshire + Mersey	Laura Elder		
<b>SOUTH</b>		<b>London</b>	
South West	Alison Cameron	London NW	Leena Karnik
Thames Valley	Georgina Hall	London NE/NC	Wendy King
Wessex	Louise Hooke	London S	Louise Soanes
South East Coast	Catherine Wynne		
<b>PPE</b>		<b>AFFILIATES</b>	
Patient rep	Tom Grew	Macmillan	Gill Levitt
Patient rep	Mathew Cooke	NCIN	M Stevens / M McCabe
Patient Advocate	Laura Clark	RCGP	Richard Neal
Patient Advocate	Dara De Burca	TYAC	David Wright
Accountable Commissioner	<b>Claire Foreman</b>	Assoc. Commissioner	<b>Sonja Tattermusch</b>

# TYA Commissioning Products

CRG advise on the following products:

- Service specs, policies and policy statements – to clarify what is routinely commissioned and to what standard
- Quality dashboards – key clinical indicators to identify variation  
<http://www.specialisedservices.nhs.uk/info/specialised-services-quality-dashboards> (examples from other CRGs)
- QIPP – clinically appropriate scheme which delivers quality and productivity improvements
- CQUIN – financial incentive scheme for stretching improvements over and above standard
- Data and pricing

# Priorities for improving outcomes in TYA

- Visibility - TYA as a whole, and site specific
- Ensuring IOG implemented (TYA MDT, choice)
- Service configurations (clear PTC and designated hospital pathways)
- Quality, quality, quality
  - Quality I (real time data on activity e.g. where are they?)
  - Quality II (data on pathway / referrals e.g. clinical trials, TYA MDT referrals)
  - Quality III (data on outcomes, especially PROMS / PREMs)

# Priorities for data

- Established a metrics sub group
- Volunteered for quality dashboard from 15/16
- Desire for linkage of existing datasets
- Need to know where patients are and referral pathways
- National Patient Survey data analysis for TYA
- Use of CQUIN to drive improvement – if the data is there and timely to demonstrate it
- Improve currency and pricing in TYA services

# What do patient tell us?

Many feedback routes – including CRG PPE members - but common themes emerge as areas for improvement:

- Quality of life is as important as survival
- Routes to diagnosis, diagnosis experience and primary care
- Choice and access to specialist services
- Peer support and role models
- Staff that understand YP and their needs
- Information – about cancer, services, late effects, support
- Psychological support and building confidence post treatment

# Thinking about TYA quality measures.....

Our starting point....

- What's most important – to young people, clinicians?
- What data is available and can we get easy access to it?
- How can we start to move from input measures to outcome measures?
- Are there proxy measures we can use in the meantime?
- How do we get support and resource to develop robust / quality PROMs / PREMs

# Suggested quality measures.....

Quality Requirement	Threshold	Method of Measurement
<b>Domain 1: Preventing people dying prematurely</b>		
Overall survival at 5 years	Unknown. Observe initially and set target once baseline known	NWCIS dataset: Include all patients over a 5 year period with a minimum follow up of 1 year
Proportion of TYA patients discussed in the TYA MDT within 28 days of diagnosis	100%	PTC and network trusts core data. % of those discussed compared to all new patients
<b>Domain 2: Enhancing the quality of life of people with long-term conditions</b>		
Proportion of patients discussed within the TYA MDT who have a holistic assessment completed and documented	100%	TYA MDT data set
Proportion of patients who have a treatment summary and care plan documented within 3 months of completion of treatment	100%	Trust cancer records

# Suggested quality measures.....

Quality Requirement	Threshold	Method of Measurement
<b>Domain 3: Helping people to recover from episodes of ill-health or following injury</b>		
Proportion of patients recruited to an NCRI clinical trial, where one exists	70%	TYA MDT
<b>Domain 4: Ensuring that people have a positive experience of care</b>		
% of patients who report receiving enough information in patient experience exercise	To be populated once mean derived from national dataset	Quality health
<b>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</b>		
% of patients dying within 30 days of start of last chemotherapy cycle	To be populated once mean derived from national dataset	NCEPOD

# Future quality measures....

- PROMs / PREMs – *to be considered and developed through PPE sub group*
- Time to diagnosis (including number of visits to GP/A+E etc)
- A palliative care metric?

# Contacts

- Stakeholder registration

[https://www.engage.england.nhs.uk/consultation/crg-stakeholder/consult\\_view](https://www.engage.england.nhs.uk/consultation/crg-stakeholder/consult_view)

- For more information about TYA CRG generally contact CRG Chair, Accountable Commissioner or Associate Commissioner
  - [rachael.hough@uclh.nhs.uk](mailto:rachael.hough@uclh.nhs.uk)
  - [claireforeman@nhs.net](mailto:claireforeman@nhs.net)
  - [sonja.tattermusch@londoncancer.org](mailto:sonja.tattermusch@londoncancer.org)
- For more information about TYA CRG Metrics sub group contact the Sub Group Chair [Alison.Cameron@UHBristol.nhs.uk](mailto:Alison.Cameron@UHBristol.nhs.uk)