What Patients Want
Laura Clark - Head of Nursing and Quality (South)

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What is Important to Young People?

Young people’s lives shouldn’t stop because they have cancer, so we treat them as young people first, cancer patients second.
Our Purpose

Working with other stakeholders to provide the very best services for TYA’s with cancer and their families.

• Ask and involve young people.
• Development of Teenage Cancer Trust units.
• Fund specialist nurses and youth support Coordinators.
• Education for young people, health professionals and general public.
• Support networks and additional services regionally.
• Funding for research focusing on treatment pathways.
• National policy development & lobbying government.

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Meaningful

What is patient consultation?
Getting the views of young people with cancer

• “No decision about me without me”

• Children and Young People’s Health Outcomes Strategy

• National Cancer Patient Experience Survey

• Patient Reported Outcome Measures
Why Ask?
Organisational Consultation

Organisational strategy & engagement

Consultation: TCTeeNation, FYSOT, research, service user activity

New activities: Youth Advisory Board, increased consultation to support policy work, regional consultation groups

Communications & fundraising

Media case studies

Attending fundraising events

Ambassadors for corporate partnerships

Photography and films
Patient Voices Report – Transforming the lives of young people with cancer
(Teenager Cancer Trust, February 2012)
I was treated on an adult oncology ward and it was the hardest experience of my life.

Stephanie, 19, diagnosed aged 17, from Hertfordshire, diagnosed with Ewings Sarcoma (right pelvis)
"Transition into adult services needs to be a lot smoother; it is difficult when you have been in children’s services for so long to move into adults. Doctors and nurses from adult services need to be more understanding."

Hannah, 20, from Devon but currently living in Aldershot studying to be a children’s nurse. Diagnosed with Acute Myeloid Leukaemia.

"There should be more services available for people like me and our age group."
After noticing I had a huge lump on my throat I went to the doctors. The Doctor told me I had adult croup and to go home to inhale steam. So I did, but it did not improve my breathing. I was practically struggling for breath walking up a couple of stairs! My parents were still concerned, so the next day my dad took me to Nottingham Queen Medicals centre’s A and E.
"I’d like to bring to your attention the direct impact on my career that my cancer had. I was aware of there being a lump in my neck around May/June 2010 when as level exams are taken and due to the severe fatigue I suffered (and still suffer from today as a result of my chemotherapy and radiotherapy treatments) caused me much trouble during my exams. Therefore my exam results did not fulfil my full potential and I feel that this should be more acknowledged by people such as yourself as this would lead to universities considering this when, as you know, university places are much more difficult to obtain.

I would very much like to become a primary school teacher as I love to work with, help and shape the minds of children and I wouldn’t want my cancer diagnosis to result in this not being able to happen."

Rebecca (Becky), 18, diagnosed aged 17, with Hodgkin’s Lymphoma
What quality care means...
What is bad quality care?
AUDIT OF TYA CANCER PATIENT’S VIEWS ON SUPPORTIVE SERVICES OFFERED BY UCLH

Questionnaire of 13/24 year olds (convenience sample cohort) N=55
(R.Hough, J.Elfer, A.Finch, M.Vernon, D.Collison, V. Riley 2012)
Important to patients

- Attitude of all staff and team working
- Access to written and other information when needed and at an appropriate rate (‘step by step’)
- Having an understanding of the disease and treatment – information needs ongoing throughout treatment
- Having contact numbers and knowing who to speak to
- Key members of team providing support
  - Ward nurses
  - CNS
  - CLIC social worker
  - Activity coordinators
- Pleasant environment
- Access to school and teachers understand you

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What's Suboptimal?

• Travelling for tests which could have been performed locally
• More social work input
• Difficult to contact ward
• More practical and emotional support for family members
• Practical advice at end of treatment
• Better contact information for the local hospital
National Cancer Patient Experience Survey (2012)

What did young people say?

• Worse diagnosis experience
• Inadequate information

Lack of confidence in healthcare professionals
What do patients tell us?

- Young people want to be around other teenagers and young adults.
- They want improved diagnostic experience.
- They want to be cared for by staff who understand their needs and know how to talk to them.
- They want meaningful treatment choices.
- They want improved age specific information.
- They worry about being able to start a family, continue their education, getting a job and having to live with the late effects of their cancer treatment for their entire lives.
How do we achieve meaningful patient engagement?
Listen!
“One of the most sincere forms of respect is actively listening to what another has to say”
Bryant. H. McGill

“I like to listen. I have learned a great deal by listening carefully, most people never listen”
Ernest Hemingway

“Wisdom is the reward you get from a lifetime of listening, when you’d have preferred to talk”
Doug Larson
Having Cancer –
Mark*, Jane* and Tom*
Life after treatment – Jane* (21)

In a crowd, but still feel alone.
Life after treatment – Jane* (21)

Big world!

Little me.

sent out to the world.
Find Your Sense of Tumour

Our annual conference is specifically for young people with cancer and gives them the chance to share experiences and learn more about their disease. Plus, with 400 young people from all over the country in one place for a weekend it’s pretty good fun too!

FYSOT - Oct 2013 at Center Parcs, Nottingham
Hear what young people say
Any Questions??????