TYA and Adult Late Effects Service at UCLH

Dr Victoria Grandage

TYA Engagement Event 25th July 2013
Summary

- Background
- UCLH Service
- Service Evaluation Audit
- Actions going forward
Background

- 1700 patients diagnosed with cancer per year in the 16-24yr age group in England.
- 400 patients between the age of 16-18, 1300 patients between the ages of 19-24yrs
- 1600 cases of childhood cancer each year in the UK who will become survivors within the TYA age group
- 40000 survivors of childhood cancer in the UK

60% of childhood cancer survivors who are more than 5 years from completion of therapy will experience at least one or more treatment- or disease-related late effects; over 30% of these problems are moderate or severe.
Consequences of treatment

• These may occur soon after treatment is completed or many years/decades later.

• Lifelong follow up of survivors is recommended.

• Multidisciplinary collaboration is required between patients and their families, oncologists and other health professionals including primary care, to ensure diagnosis, counselling and timely initiation of appropriate treatments.

• As a patient group they may attract particular benefit from interventions to encourage healthy lifestyle.
**Aims of Long term Follow-up**

- Early diagnosis and intervention of late effects to improve QOL
- Preventive care targeted at reducing risks of late effects to benefit the health and quality of life of survivors.
- To provide specialist advice and treatment plans for patients treated for cancer.
- To facilitate transition from paediatric and adolescent services to adult services.
- To provide all patients and carers with a point of contact within the multidisciplinary team, for queries relating to an individual’s management plan.
- To ensure that protocols, guidelines and standard operating procedures are developed and kept updated for all aspects of management and treatment.
UCLH Late Effects Service

Late Effects Coordinator - Onemeotite Eyituoyo
Clinical Nurse Specialist - Susan Mehta
Medical lead - Dr Victoria Grandage
New appointment to Snowcroft fellowship - Dr Rachael Windsor
General manager - Emily Collins
UCLH Service-Patients

- GOSH-patients currently transitioned directly into the TYA late effects service at UCLH at the age of 18-20 years usually via a nurse led transition clinic.

- UCLH CYPICS-patients treated between the age of 13 yrs and the 20th birthday.

- UCLH adult late effects service-patients treated either as a child, teenager, or young adult and transitioned into the late effects service.

- Patients returning from shared care hospitals at age of 16-18 yrs.

- Young adult patients treated at designated centres-pathway needs to be defined.
Multidisciplinary Clinic

- An adult multidisciplinary late effects clinic was established in Jan 2010. This provides level 3 care predominantly for adult survivors of childhood/adolescent cancer.

- The clinic runs monthly on the second Monday afternoon of the month. The clinics are themed so that general oncology patients are seen together as are bone marrow transplant survivors.

- Referrals into this clinic are predominantly from GOSH and a few are transitioned from the adolescent level 3 clinic.

- A separate Sarcoma LTFU clinic runs along side this clinic and is able to avail itself of the specialist expertise as necessary.
<table>
<thead>
<tr>
<th>Position</th>
<th>Name</th>
<th>Speciality</th>
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<tbody>
<tr>
<td>Consultant Haematologist*</td>
<td>Dr Victoria Grandage</td>
<td>BMT and General</td>
</tr>
<tr>
<td>Consultant Paediatric Oncologist</td>
<td>Dr Tanzina Chowdhury</td>
<td>General</td>
</tr>
<tr>
<td>Associate Specialist Late Effects</td>
<td>Dr Ali Leiper</td>
<td>BMT and General</td>
</tr>
<tr>
<td>Consultant Clinical Oncologist</td>
<td>Dr Yenching Chang</td>
<td>General</td>
</tr>
<tr>
<td>Consultant Endocrinologist</td>
<td>Dr Stephanie Baldeweg</td>
<td>General and BMT</td>
</tr>
<tr>
<td>Consultant Endocrinologist*</td>
<td>Dr Helen Spoudeas</td>
<td>Adolescent</td>
</tr>
<tr>
<td>Consultant Gynaecologist and Reproductive Health*</td>
<td>Ms Melanie Davies</td>
<td>BMT and General</td>
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<tr>
<td>Consultant Nephrologist*</td>
<td>Prof Robert Unwin Dr Andrew Hall</td>
<td>BMT and General</td>
</tr>
<tr>
<td>Clinical Nurse Specialist in Late effects</td>
<td>Susan Mehta</td>
<td>BMT and General</td>
</tr>
<tr>
<td>Nurse Consultant Endocrinology</td>
<td>Sofia Ilahana</td>
<td>BMT and General</td>
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Lower Level Clinics

• TYA level1/2 clinics 1\textsuperscript{st} and 4\textsuperscript{th} Monday of the month (Dr Grandage/Dr Windsor)

• Adult level 1/2 clinic 3\textsuperscript{rd} Monday of the Month (Dr Grandage/Dr Windsor)

• Nurse Led Transition clinic 1\textsuperscript{st} and 3\textsuperscript{rd} Wednesday of the month with a plan to increase to weekly (Susan Mehta)
Evaluation of the TYA Late Effects Service

The aims of the audit were:

• To detail activity data on all patients invited to attend the late effects service for children, teenagers and young adults at UCLH, to make informed decisions for local service development.

• Could a generic audit tool be constructed that would be relevant to all LTFU services
Methodology.

Data was collected prospectively using a standardised audit tool:

- Demographic and clinical profile of the patient population.
- Capacity of individual clinics run by the service and attending consultants/nurses, including proportion of DNA appointments (‘Did Not Attend’)
- Relationship between LFTU and non-oncology services (referrals to or from other services)
- Type of investigations ordered as part of LTFU
- Identification of patient needs (information on education, travel, financial aid, etc.)
- Appointment outcomes (referral to LTFU in primary care, at other hospital, same clinic etc.)
Results- Service Activity

- Between 01 December 2012 and 11 February 2013 a total of 117 patients had been booked for follow-up at the UCLH Late Effects Service.

- The overall DNA rate = 31%; however, not all DNA events had been recorded appropriately.

- New referrals presented 24% of those attending whilst 51% of patients were seen as part of continued follow-up.

- The majority of patients (65%) were aged between 18 and 34 years.
## Patient Demographics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Male</td>
<td>43</td>
<td>48%</td>
</tr>
<tr>
<td>Female</td>
<td>46</td>
<td>52%</td>
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<table>
<thead>
<tr>
<th>Age Group</th>
<th>Count</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>&gt;18</td>
<td>22</td>
<td>28%</td>
</tr>
<tr>
<td>&gt;25</td>
<td>41</td>
<td>51%</td>
</tr>
<tr>
<td>&gt;35</td>
<td>13</td>
<td>16%</td>
</tr>
<tr>
<td>&gt;45</td>
<td>3</td>
<td>4%</td>
</tr>
<tr>
<td>&gt;55</td>
<td>1</td>
<td>1%</td>
</tr>
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</table>
Referral Source/Appointment type

<table>
<thead>
<tr>
<th>Appointment Type</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>New Patient from TYA</td>
<td>1%</td>
</tr>
<tr>
<td>New Patient from GOSH</td>
<td>9%</td>
</tr>
<tr>
<td>Referral from other</td>
<td>2%</td>
</tr>
<tr>
<td>Continuing LTFU</td>
<td>19%</td>
</tr>
<tr>
<td>Re-entry into follow-up</td>
<td>67%</td>
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</tbody>
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Patient Distribution

Clinic appointments at UCLH

- Low Risk Clinic: 18%
- MDT (BMT): 8%
- MDT (General): 36%
- Nurse Led: 15%
- Sarcoma Clinic: 24%

Seen by (as % of patients)

- AL: 11%
- JW: 20%
- MD: 1%
- AH: 10%
- SB: 10%
- SL: 0%
- SM: 17%
- TC: 8%
- VG: 21%
- YC: 8%
- Other: 0%
Diagnostic groups

![Bar chart showing diagnostic groups](chart_image)

- BMT: 15%
- CNS Tumour: 0%
- Germ Cell: 0%
- Hepatoblastoma: 0%
- Leukaemia: 25%
- Lymphoma: 15%
- Neuroblastoma: 1%
- Rhabdomyosarcoma: 4%
- Sarcoma: 20%
- Wilms: 7%
- Other: 2%
## Levels of Care

<table>
<thead>
<tr>
<th>LEVEL OF CARE</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
</tr>
<tr>
<td>Level 1</td>
<td>23</td>
</tr>
<tr>
<td>Level 2</td>
<td>16</td>
</tr>
<tr>
<td>Level 3</td>
<td>26</td>
</tr>
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**Graph: Level of Care**

- **Level 3**
- **Level 2**
- **Level 1**
- **Not recorded**

Excellence care through partnership.
Documentation

- The audit sheet records whether or not a patient has a treatment summary and a care plan at the time of the clinic attendance.

- Preliminary analysis of the audit sheets suggested a high compliance of the service with the national target that all patients should have treatment summaries and care plans.

- However, further investigation revealed that participating clinicians equalled the presence of a standard clinical letter to that of a treatment summary and care plan. Thus, subsequent audit sheets were amended to define a treatment summary and care plan.
Appointment Outcome

Follow-up Plan

- Further appointment this clinic: 66%
- Further appointment (different clinic at this service): 31%
- Referred elsewhere: 2%
- Other: 1%
Conclusions

• About 31% of patients were new to the service and 66% of patients were given a follow-up appointment within the next 12 months; with only 3% of patients discharged to primary care or referred to another LTFU service, compounding capacity issues.

• The service has a high DNA rate of 31%, the reasons for which will be explored in a subsequent audit.

• The majority of patients were seen in the clinic that was most appropriate to the level of care they required.

• The audit indicated that >75% of patients had a treatment summary and care plan but this data was dependent on the clinicians definition and expectations on these documents.
Conclusions

• Information was available to meet the needs of ~95% of patients

• A significant proportion of patients in LTFU were already known to or referred to other non-oncology services, particularly endocrinology

• Feedback from clinicians identified a subset of audit questions that are sufficiently generic to be applicable and relevant to all LTFU services. However, the team strongly felt that to obtain useful, high quality data the audit has to be fully implemented and owned by the respective LTFU team
Actions

- Audit will be fully integrated into the service and rolled out across all TYA LTFU clinics, it will be conducted on an ongoing basis and analysed quarterly.
- Handover of analysis spreadsheet and IT knowledge from London Cancer pathway manager to local service manager.
- Development of audit focusing on reasons for not attending to lower DNA rate
- A ‘buddy sheet’ explaining definitions / audit questions will be produced to train clinicians in accurate completion of the audit
- Business plan for the development of the UCLH LTFU service will be written on the basis of the audit data
Actions

• Improve efficiency of clinics, identify reasons for DNAs and try and address them.

• Ensure patients seen in appropriate level of clinic for their needs.

• Develop infrastructure including database that allows for patients to be safely discharged from the service to primary care/supported self management

• Develop novel methods of follow up including virtual clinics that allow for less hospital based follow up
Actions

- Audit looking into LTFU offered to young Adult patients within Cancer services at UCLH
- Define pathways for Young adult patients treated at designated centres and at UCLH to gain access to transition and LTFU if necessary