



Key points – Get Started with Transition

Friday June 24th 9 am – 12 noon

Timestamp	Presentation	Lead
00:00:00	Setting the Scene for Adolescent Health  Zahra Sarwar - Presentation.pdf	Zahra Sarwar z.sarwar@nhs.net Youth Worker KAOS Team, King's College Hospital
<ul style="list-style-type: none"> • King's Adolescent Outreach Service (KAOS) consists of two youth workers, two clinical leads, and 35 to 40 volunteer clinicians. After funding was provided for one year from Redthread (a national youth worker charity), using data collated in that year, a case was made and approved to for substantive positions. • Using Redthread's definition of a youth worker and the clinical team's understanding of the care needed by young people a job description was created. They act as patient advocates. • The KAOS team engage with any 13 to 25 year old inpatient though the primary focus is 16 to 21 who are in adult wards. This is because it's considered that at this age for the most part patients should be able to turn to their primary care providers with their issues before needing to go through A&E and being unwell enough to be admitted as an inpatient. Also any clinician in the hospital can refer patients to youth workers. • The You and Your Health questionnaire designed by Dr Steph Lamb from the Well Centre is used with each patient though they adopt a conversational way of talking. Patient are often more honest with youth workers and this conversation allows the youth worker to then refer the patient to the right service for them. • Working collaborative with all the other support services is key to delivering the best care for patients. The volunteer clinicians are part of an on-call rota so youth workers can call them when they need advice and then there are other services, e.g. schools, violence team, safeguarding team, sexual health team etc., that is important to work with closely. • All data is recorded about the patient, the appointment, the result etc. for quarterly reports and to review readmission rates. • Top tips given: <ul style="list-style-type: none"> ➢ Use as much jargon free language as possible - "meet young people where they are at" ➢ Try to take your time, patients will know when clinicians are rushing appointments ➢ Humanise the patient and yourself, tell them a little about yourself, show that you see that they are a person ➢ Have patience, remember that staff can find the hospital setting entirely normal but to patients it is not a comfortable place ➢ Be kind to others but also be kind to yourself and know when you need to step back for your own wellbeing. • Family engagement is not dealt with through the KAOS team due to time constraints. 		
00:22:11	Learning from experience  Emma Potter - Presentation.pdf	Emma Potter Emma.Potter@rmh.nhs.uk Transition Practitioner, The Royal Marsden NHS Foundation Trust
<ul style="list-style-type: none"> • The Children's Cancer Service Specification (as published by NHSE) states that all young people diagnosed with cancer up to the age of 19 are referred to a primary treatment centre. This means most children have shared care between primary centres and one of the 16 Paediatric Oncology Shared Care Units (POSCU) but access to POSCU's vary depending on the provider. • Through networking and hearing from others, the South Thames Children & Young People Operational Network Transition Working Group was formed. 		

- Pathway mapping workshops were held with a total of 44 healthcare professionals.
- Although a pathway can be mapped, the challenges become who would be doing which part of the pathway, where it would happen, at what age, etc.
- Patient involvement was key, with eventually 45 young people & parents providing their input. This was obtained just by ringing patients and offering them the opportunity to have their say around transition. This helped build a much fuller picture around transition.
- The initial phase was scoping, then developing the aims of the project. Currently it is in the testing and implementing phase with the final phase being to spread good practice though it was emphasised that it will need continuous oversight and improvement.

00:38:54

Transition within a chronic disease setting – the Congenital Heart Disease experience



Lynda Shaughnessy - Presentation.pdf

Lynda Shaughnessy

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- The British Heart Foundation noted that patients were often lost to follow up appointments and help improve this, 6 adolescent CHD nurses were funded for three years. The network recognised that young people needed to be empowered to understand when they needed access and how to access different services.
- After treatment and transfer to adult services, patients often think that they are cured. There was an educational task to make sure patients know they will always have to have follow up appointments.
- The main focus initially was to try and reduce those lost to follow up. To do this, the data around this was obtained to see how many lost and what the main predictors were of non-attendance; it showed those who engaged were associated with improved survival.
- Sometimes it's expected that patients should know everything before going into adult services, but that was found not to be the case and that support needs to continue into adult services and that all stakeholders are communicating.
- Choosing the right model of care for each patient is important, there is no one-size fits all. There are different options such as the adolescent clinic model, joint clinic model, traditional medical model and a nurse led model, which all have their own pros and cons.
- A pan-London patient day was introduced as an annual event for young people with CHD where they can learn about lifestyle issues, diet, sexual health, alcohol etc. They also enjoy meeting others similar to them.
- The network also participates with peer review process with the Stepstones project which has been running for 7 years. The process looks at transition pathways and collects quantitative and qualitative research and provides feedback as to where the model of care works well and where further improvements are needed. As a part of this project, they produced the Gothenburg Young Persons Empowerment Scale which is now being used in the CHD transition clinics to look at how empowered patients are before they go to adult services to know how much support they need.

00:59:57

Engaging young people

Hannah Phillips

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Patient

- Hannah discussed how it was for her personally when moved to adult services and how challenging it was.
- Top tips:
 - Improvement the environment for adults services, it can be cold and intimidating.
 - Better education for both staff and patients
 - Ensuring that you give young people a platform during service development
 - Improve communication between paediatric and adult services and patients

- “You treat a disease you win you lose. You treat a person and I guarantee you will win no matter the outcome” – Patch Adams.

01:14:41

Challenges in transition: perspectives from the adult side



Emma Matthews -
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Emma Matthews

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- To form a transition service, it was recognised that an integrated MDT service is needed.
- Length of appointments was one of the first things to be addressed since regular adult clinics only allow 30 minutes for a new appointment or 40 minutes for specialist clinics. For the transition clinic, the challenge was to convince management for appointments to be an hour long.
- There are also a number of other challenges around communication between services, having the resources to support this, training the staff to make sure they have the expertise needed, changing clinic templates, the age of transfer, etc.
- For very specialised treatment, there are challenges since resources and facilities are more limited than usual.
- Obtained funding for a transition nurse to help transform the transition pathway.
- It's important to recognise transition as a separate service though this needs the infrastructure and admin support in place to work effectively. There also needs agreement around the age of acceptance so there isn't a gap in the service.

01:26:56

Introduction to National frameworks and documents



Nigel Mills -
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Nigel Mills

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- Recommended to read “From the Pond into the Sea”, a CQC report and the NICE transition guidelines NG43. There are 56 recommendations but the outcome measures are what the CQC measures when they inspect.
- There are five key standards from the nice guidance:
 - To begin the transition process in year 9
 - To have at least a once annual meeting on transition with patients & parents before they transition
 - To have a named worker who would coordinate transition before, during and after.
 - To meet their adult service practitioner before moving across
 - To ensure adult and paediatric services work collaboratively to engage patients when they are not engaging post-transition.
- The core capabilities framework is currently being formalised which will outline the expected skill set for staff supporting transition. It recognises that everyone coming in contact with young people should know how to support them in a way that different to children and different to adults.

Additional documents that were mentioned will be provided on the adolescent health section of the STPN website.

The next steps are to form working groups that will address the below:

- Working with Youth workers
- Benchmarking and frameworks
- Developing Youth Forums
- Sharing good practice and supporting each other
- Working with adult services

We will be first arranging a Transition Steering Group in September to develop objectives and tangible next steps to create effective working groups.