Abstract
The Thames Valley Strategic Clinical Network carried out a 12 month project with the aim of developing a more structured, coordinated and developmentally appropriate approach for young people moving from children’s to adult’s healthcare provision by piloting the ‘Ready Steady Go’ transition programme. Two Network Transition nurses were appointed to support the project. One nurse was hosted at the Royal Berkshire Foundation Trust (RBFT) for one year and the second nurse was based at Oxford University Hospitals (OUH) for 6 months. This report is a summary of ‘Phase 1’ of the project and includes the end of year reports by both of the Network Transition Nurses. It sets out the plan for ‘Phase 2’ of the project which is to continue to support acute Trusts across the region to implement and embed Ready Steady Go.

Polly Schofield (Network Transition Nurse, RBFT)
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2 INTRODUCTION

The aim of this report is to give background and rational as to why it is vital that health services get transition right for young people and why it is a key priority for the Thames Valley Strategic Clinical Network (Children and Maternity). The report will describe the first phase of the transition project provide a full evaluation. It also sets out the plan for the second phase, which is to continue to support acute Trusts across the region to continue to develop transition services.

There has been a rapidly evolving landscape of guidance and legislation which influence the development of transition services, most notably the National Institute for Clinical Excellence (NICE 2016) Guideline on Transition from Children’s to Adult services, the Care Act (2014) and the Special Educational Needs and Disability (SEND) reforms introduced by the Children and Families Act (2014). The project outcomes were driven by the requirements and recommendations made in these documents to ensure provider trusts in the Thames Valley and Milton Keynes fulfill their duty of care and deliver the best support possible to young people moving into adult services.

2.1 KEY ISSUES AROUND TRANSITION

There is a wealth of policy and guidance on agreed principles in respect of good transitional care, but there is also evidence that these principles are often not reflected in practice (Beresford and Cavet, 2009, NHS Diabetes report, Watson 2005, Singh 2009). Some of the most notable issues around transition are:

1. Lack of clarity of transition pathways

A review into transition services carried out by the Care Quality Commission (CQC, 2013) highlighted that there was inconsistent and often poor information from children’s services and no clear pathway for young people and their parents about the changes they can expect as they move into adult services. This led to a lack of understanding of the process of transition. Many of the professionals delivering care disclosed to the CQC that they were also not clear about the process within their own organisations.

2. Poor communication between services

More children with long-term conditions now live into adulthood (McDonagh 2006), therefore, there is a growing need for specialised care and services to ensure seamless transition of young people to adult health care services. Transitions between care settings and services are significant points at which people are particularly vulnerable to losing continuity in the care they receive (Goodwin et al 2010) so it is vital there is effective communication between services.

3. Poor transition planning impacts long term health outcomes

The CQC (2014) found that 80% of the young people in the review did not have a transition plan that included their health needs. NICE (2016) recommend that young people with long term conditions should have a transition planning document that is started early, is developmentally appropriate and involves the young person and their parents / carers.
Disengagement from health services and or poor disease knowledge and management as a result of a poorly planned transition can impact on long-term health outcomes for children and young people (Viner 1999). Research suggests that disengagement from services can be the result of a combination of psychosocial and pubertal changes that occur during adolescence such as erratic eating and exercise, risk taking/antisocial behaviours, family stressors and self-image problems (Patten and Viner 2007). All these factors can significantly impact on the young person’s ability to manage their illness independently, including adherence to medication regimes, attendance at outpatient clinic appointments (McDonagh and Viner 2006).

Evidence suggests that A&E attendances and hospital admissions rise for children and young people with long term conditions, roughly from the age of 15 years upwards and that Did Not Attend (DNA) rates for outpatient clinics increase between the ages of 16-19 (McDonagh, 2006). This could indicate that there is a peak in non-compliance around the time of transition which could impact both on the health outcomes of the young person and will have financial implications for health services.

4. Transitional care - resource allocation

The CQC (2014) review into transition and the NICE (2016) guidelines both recommend that there should be a lead professional to support the young person and their families through transition. However, the CQC review found that 50% of families did not have a lead professional and health professionals said that the parents were often the main coordinators of care and services. The CQC reported that there could be three main reasons for this. Firstly, there is a lack of resources and capacity in children’s services to manage the existing workload, which is increasing. Secondly, adult health services are not engaging in transition planning with under-18s because they are not funded to do this. Finally, GPs are not routinely involved in the care of young people with complex needs as children, so are not in a position to be coordinating their transition, but then they will have a key role when the young person becomes an adult.

3 Transition Project Overview

The overall aim of this project was to improve transition from children to adult services in acute trusts across the Thames Valley and Milton Keynes by creating a standardised approach across the region. The Children's TVSCN quality improvement lead worked with two Network appointed Transition nurses, to achieve the project aims. The first nurse was hosted at the Royal Berkshire Foundation Trust (RBFT) for one year and helped support the implementation of the overall project objectives in addition to managing the Transition project in RBFT. The second nurse was based at Oxford University Hospitals (OUH) for 6 months and supported the implementation of a nationally recognized transition programme ‘Ready Steady Go’ in the acute trusts across the region. The Oxford and Reading posts differed, but complemented each other in achieving the overall objectives of the project.

By building on the nationally respected transition programme ‘Ready Steady Go’, developed by Southampton University Hospital, it was anticipated that this project could be highly successful in creating a model that could be replicated nationally. It is believed that an effective transition process which supports young people is associated with significant financial savings in the longer term. In this document, the acronym ‘RSGH’ refers to the entire ‘Ready Steady Go’ programme and the accompanying document, ‘Hello to Adult Services’.
3.1 **JOINT NETWORK TRANSITION NURSE PROJECT AIMS:**
- To create a best practice pathway for transition that could be used across the Thames Valley and Milton Keynes, which acknowledges the publication of any commissioning service specifications
- To set up a transition working group across the Network to include representation from all Trusts, adult and paediatric clinicians, GPs and commissioners.
- To organise a transition workshop following collation of the pathways and protocols to promote a standardised approach to transition services across the Network
- To create a toolkit of resources needed to develop transition services in acute trusts

3.2 **RBFT NETWORK TRANSITION NURSE PROJECT AIMS:**
- To identify an executive lead for transition at RBFT
- To set up a RBFT transition steering group to support a trust wide approach to developing transition services
- To ensure patient and parent engagement in developing transition services
- To document the current service provision for transition within each speciality and any protocols in place in RBFT
- To analyse data relating to Emergency Department attendance and Out Patient Clinic attendance for young people in 2 patient cohorts at RBFT
- To manage a one year pilot of the transition programme ‘Ready Steady Go’ (RSGH) in 2 patient cohorts
- To write a trust transitions policy, that could be replicated in other trusts

3.3 **OUH NETWORK TRANSITION NURSE PROJECT AIMS:**
- To develop an educational programme supporting implementation of Ready, Steady, Go
- To develop educational materials related to transition
- To roll out educational sessions in all the acute trusts across the Thames Valley

4 ‘**READY STEADY GO’ AND ‘HELLO TO ADULT SERVICES’ OVERVIEW**

‘Ready Steady Go’ and the accompanying document, ‘Hello to Adult Services’ are generic transition programmes for young people (YP) with a long term condition aged 11+ years which was developed at the University Hospital Southampton. In this document, the acronym ‘RSGH’ refers to the entire ‘Ready Steady Go’ programme and the accompanying document, ‘Hello to Adult Services’. RSGH is a structured, but where necessary adaptable, transition programme which can be used across all sub-specialties. A key principle throughout RSGH is ‘empowering’ the Young People (YP) to take control of their lives and equipping them with the necessary skills and knowledge to manage their own healthcare confidently and successfully in both paediatric and adult services. This is initiated through the completion of a series of questionnaires. The questions are deliberately broad providing the opportunity for the healthcare professional to ask targeted questions specific to their condition. The answers are used as a basis for starting discussion and the questionnaires are designed to prompt appropriate engagement over potentially difficult issues such as sex and psychosocial concerns. Any issues which may arise are carefully addressed prior to transfer to adult services.

The aim of RSGH is that the YP will be able to manage their healthcare successfully, not just in their local adult service but in any adult service across the country - whether or not they have previously met the
adult physician or GP to whom their care is transferred. Where the YP has learning difficulties the carer works through the RSGH programme with the YP engaging as much as possible.

5 PROGRESS ON JOINT PROJECT AIMS

5.1 TO CREATE A BEST PRACTICE TRANSITION PATHWAY

Method:
The pathway was developed following the outcomes from the RSGH pilot at RBFT and in response to the discussions that took place with clinicians across the Thames Valley when delivering the RSGH training. The final version follows consultation with the TVSCN Transition Task and Finish group, clinicians and patient / parent groups. The pathway is based on the RSGH programme and aims to provide a clear guide to clinicians on transition timings and what should happen at each stage. The pathway was designed to encourage professionals to use a staged approach to transition planning, even if the RSGH programme is not fully embedded in their areas of work. It also acts as a guide for young people and their families and ensures providers are giving clear information about their transition service provision.

Progress
The pathway is now complete (see appendix 1) and has been approved by the TVSCN Transition Task and Finish group.

Promotion and publication
The pathway has been included in the TVSCN Transition Toolkit which is available on the TVSCN website http://tvscn.nhs.uk/networks/maternity-and-childrens/children/transition-children-adult-health-services/ and is also available on the OUH intranet site. It was promoted at the TVSCN transition event in December, 2015 and is included in the RSGH teaching sessions that have been delivered across the Thames Valley. The pathway has also been included in the RBFT Transition policy and is available on the Reading, Wokingham and West Berkshire ‘Local Offer’.

Next Steps
There is a review date of one year on the pathway and it will be updated by the TVSCN Transition group as the transition project progresses. It is anticipated that in one year, all acute trusts in the region will have included it in their transition policies. There have also been discussions with commissioners about including it in service specifications.

5.2 TO SET UP A TRANSITION WORKING GROUP ACROSS THE NETWORK

Method
A Transitions event was held by the TVSCN in December 2014 and delegates were invited to join a transitions ‘task and finish’ group. There was a good response and the group had representation from clinicians and commissioners from across the Thames Valley. The first meeting was held in February 2015 and met quarterly throughout the year. The aims of the group were to:

- Promote and support implementation of RSGH across the Thames Valley and Milton Keynes

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1 The ‘Local Offer’ gives children and young people with special educational needs or disabilities and their families information about what support services the local authority think will be available in their local area. Every local authority is responsible for writing a Local Offer and making sure it is available for everyone to see.
• Support the development of an RSGH educational programme
• Share good practice and ensure nationally recognized tools and methodology were being promoted across the region.
• Share information and lessons learned relating to the transition project work being undertaken within RBFT
• Support provider trusts in the development of a transition policy
• Develop a Best Practice transition pathway

Progress:
In February 2016, the group had been meeting for one year and the aims above have now been achieved and are reported on throughout this document. As a result of this, the group has been dissolved. The members will remain on a mailing list and the Network Transition Nurse will update the group on any new initiatives and achievements in transition services across the region.

5.3 AIM: TO ORGANISE A TVSCN TRANSITION WORKSHOP

Progress:
In December 2015, an event was held in Oxford with the aim of trying to capture the teams that had been unable to attend or arrange a training session on the RSGH programme, and to provide professionals with some practical advice on implementation. The objectives of the day were to:
• Help delegates understand what the SCN is and how it could add value to their service
• Demonstrate what resources are available to support transition locally and nationally
• Explain what is currently happening to develop transition services in the region
• Give practical advice on ‘what works well’ from a range of speakers

There were 6 speakers from across the Thames Valley and included both paediatric and adult clinicians. We were also fortunate to have two clinical nurse specialists from Southampton University Hospital to deliver a training session on RSGH. The objectives of the day were:
• The TVSCN Transition toolkit – what is available and how to access support with developing transition services
• How to engage young people in transition planning
• How to use RSGH for young people with profound and multiple learning difficulties
• Using ‘Hello’ in the adult service
• How to create Transfer clinics

Each delegate was given a pack with key elements of the toolkit, including a copy of the RSGH programme and the TVSCN Best Practice Transition Pathway, to take back to their own organisations. Approximately 60 professionals from across the Thames Valley and Milton Keynes attended and the evaluations were extremely positive. The event was very useful in making key contacts and identifying potential transition champions for the TVSCN Best Practice Transition Group.

5.4 AIM: TO CREATE A TOOLKIT OF RESOURCES NEEDED TO DEVELOP TRANSITION SERVICES IN ACUTE TRUSTS

Method:
The toolkit was develop by the network transition nurses by identifying and developing resources that would enable clinicians to deliver the RSGH programme and develop transition services in their areas of work. Recourses in the toolkit include:
• RSGH documents in PDF form
‘RSGH Frequently Asked Questions’
TVSCN Best Practice Transition Pathway
‘Understanding the Mental Capacity Act’ leaflet for young people and families
‘Signposting to local services’ document for professionals
Acute Trust Transition Policy template
Hospital steering group Terms of Reference
Patient / carer Transition questionnaire

Progress:
The toolkit is now complete and is available on the TVSCN website http://tvscn.nhs.uk/networks/maternity-and-childrens/children/transition-children-adult-health-services/ and is also available on the OUH intranet site. It was promoted at the TVSCN transition event in December, 2015 and is included in the RSGH teaching sessions that have been delivered across the Thames Valley.

6 RBFT NETWORK TRANSITION NURSE AIMS:

6.1 AIM: TO IDENTIFY AN EXECUTIVE LEAD FOR TRANSITION AT RBFT
The Director of Nursing at RBFT is now the Executive Lead for Transition at RBFT and is the Trust’s transition policy lead.

6.2 AIM: TO SET UP A RBFT TRANSITION STEERING GROUP

Method:
An email was sent to all consultants and clinical nurse specialists (CNS) in the trust in January 2015 with the project brief and proposed terms of reference for the transition project steering group. The RBFT Transition nurse also emailed the Patient Leader2 coordinator to try and identify a patient representative for the group. The group had its first meeting in February 2015 and continues to meet every 2 months. It is chaired by an adult neurorehabilitation consultant and has representation from adult and paediatric services and a Patient Leader. The aims of the group are:

- To map current transition pathways for identified specialties (initially, Neurodisability, Epilepsy and Diabetes)
- To establish the current number of 11-18 year olds in each identified specialty
- To engage young people in developing a transition service
- To pilot the RSGH transition programme and develop transfer pathways in 2-3 pilot clinics
- To write a Trust Transition Policy
- To identify an executive Lead for Transition who will oversee the provision of services for young people in both Paediatric and adult care to ensure they are fit for purpose.

Progress:
This group will continue to meet while the RBFT Transition Nurse is still in post to support a trust wide roll out of RSGH and ensure compliance with new policy and the upcoming NICE guidance on transition. The terms of reference and the work plan will be updated to reflect a change in the work plan.

Patient Leaders to work at a strategic level at the RBFT represent patients, to effect change, to design services and to improve patient pathways and systems of care.
6.3 TO ENSURE PATIENT AND PARENT ENGAGEMENT IN DEVELOPING TRANSITION SERVICES

Method
In January 2015, a survey was undertaken to find out from young people and their families how they found their transition and what they feel could be improved. Questionnaires were sent out to 72 families in cohorts A&B (cohort A: Neurodisability, cohort B: Diabetes) who had been transitioned to the adult services at the RBFT over the past 2 years.

Results:

Figure 1: Neurodisability Post Transition Questionnaire (Parent feedback)

Cohort A: Post Transition Questionnaire Feedback (Parents)

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child had a written health transition plan</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>2. My child was between 11-13 when transition planning started</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>3. My child had a key person to support them through transition at the RBH</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. The RBH supported my child with all aspects of transition, not just their health transition (e.g. social, emotional, educational)</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>5. I was satisfied with the transition service we received at the RBH</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>

Figure 2: Neurodisability Post Transition Questionnaire (Young person’s feedback)

Cohort A: Post-transition Questionnaire Feedback (YP)

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I had a written health transition plan</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>2. I was between 11-13 when transition planning started</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>3. I had a key person to support them through transition at the RBH</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>4. The RBH supported me with all aspects of transition, not just my health transition (e.g. social, emotional, educational)</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. I was satisfied with the transition service I received at the RBH</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
A full list of the comments made by young people and their parents / carers can be found in Appendix 3, but themes included:

- Concerns over the adult wards environment
- Lack of transfer clinics
- Lack of transition planning
- Lack of information
- Lack of communication about transition plans with families and outside agencies
The results of the survey were shared with the RBFT Transition steering group to ensure that the project outcomes would address the concerns. As a result of the survey results, a patient representative was invited to join the transitions steering group.

Next steps:
The RBFT steering group will work to identify the best method to evaluate the impact of the RSGH programme in the pilot cohorts. This will be done by January 2017, by which time, the programme will have been running for 2 years and will take into account the recommendations made by the TVSCN Best Practice Transitions group about patient experience surveys.

6.4 AIm: To map the current service provision for transition within each speciality at RBFT

Method:
An Excel document was created and distributed to consultants and Clinical Nurse Specialists in all departments and they were asked to populate it with their current transition service information. The document was then shared with the steering group where gaps in service and areas for service development were identified.

Progress
This exercise was completed in January 2015. The document identified that there were significant gaps in transition services at the RBFT. If there is a handover process, it varies from holding transition clinics, to a discharge letter to the GP. In some areas, there is no equivalent adult service, e.g. Community Paediatrician and Allergies. The age of transition varies throughout the trust which is likely to cause confusion for both patients and clinicians. This could potentially impact on clinical outcomes in terms of a lack of continuity of care and a lack of adequate clinical handover.

Next steps:
In order to provide a standardized approach to transition services across the RBFT, a trust transition policy and accompanying guidelines have been developed. This mapping exercise will be repeated in December 2016 and it is anticipated that the gaps in service will be reduced and the transfer process will be more consistent across the trust.

6.5 AIm: To analyse data relating to emergency department (ED) attendance and outpatient clinic attendance

Rational:
Evidence suggests that A&E attendances and hospital admissions rise for children and young people with long term conditions, roughly from the age of 15 years upwards and that ‘Did Not Attend’ (DNA) rates for outpatient clinics increase between the ages of 16-19 (around the time of transition to adult services). The TVSCN data analyst carried out analysis of relevant RBFT data to see Emergency Department (ED) and DNA rates rise during the time of transition in the two pilot cohorts.

DNA Data
Data Source:
- Royal Berkshire Hospital (with permission from the Caldicott Guardian)
- Outpatient clinics (OP)
- Attendance and non-attendance for all specialties
- Date range January 2010 to January 2015
- Age range 14-25

**Methodology:**
Patient flow was linked and pulled into 2 analysis criteria:
1. Patients who had clinic appointments starting from age 16 (or under) and had clinic appointments for 2 years+
2. Patients who had clinic appointments starting from age 14 until age 18 or older (had clinic appointments for 5 years or more)

**Results:**

<table>
<thead>
<tr>
<th>Age</th>
<th>Attended</th>
<th>DNA</th>
<th>No of clinics</th>
<th>DNA Rate</th>
</tr>
</thead>
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<td>10</td>
<td>149</td>
<td>7%</td>
</tr>
</tbody>
</table>

**Findings:**
The results of 2 analysis criteria are same that DNA rate is slightly higher transition group

**Assumptions/ limitations:**
• There were no diagnosis codes at outpatient records, so patients may have more than one different medical condition.

ED data:
Data Source:
• ED diagnosis codes: 241 and 301 (diabetes and Epilepsy)
• All ages
• Date range January 2010 to January 2015

Methodology and limitations:
It was not possible to link the patient flow to identify if there was an increase in ED attendance as a result of reducing attendance at OP clinic appointments.

Results:
Analysis of data showed there was not a significant increase in ED attendance for patients between the ages of 18-25.

Conclusions:
The findings from the DNA rates analysis could indicate that there is a peak in non-compliance around the time of transition which could impact both on the health outcomes of the young person and will have financial implications for the Trust. Additional consequences of poor transitions could include broken relationships with health and social care practitioners and gradual disengagement with services.

Actions:
Staff need to be aware of the DNA protocol for under 18s but also need to acknowledge that vulnerable patients over the age of 18 need to be followed up when they DNA clinic appointments. This is now included in the transition policy and associated guidelines.

6.6 AIM: TO WRITE A TRUST TRANSITIONS POLICY, THAT COULD BE REPLICATED IN OTHER TRUSTS
This is now complete and the policy was approved by the trust wide policy group in January 2016. The policy can be found in the embedded document below:

The policy is available on the TVSCN website http://tvscn.nhs.uk/networks/maternity-and-childrens/children/transition-children-adult-health-services/. It was promoted at the TVSCN transition event in December, 2015 and is included in the RSGH teaching sessions that have been delivered across the Thames Valley.

6.7 AIM: TO MANAGE A ONE YEAR PILOT OF THE TRANSITION PROGRAMME ‘READY STEADY GO’ (RSGH) IN 2 PATIENT COHORTS
This pilot is now complete. The full pilot evaluation document and the recommendations for rolling out trust wide can be found in the embedded document below and in appendix 4.
The project team concluded that it was too early to fully evaluate the impact that the RSGH programme was having on their patients, but all believed it had potential to have positive outcomes for young people. The team agreed that a transition survey should be re-issued in January 2017 once the process has been embedded and young people have been able to fully access one of the programme stages. Three out of the four clinicians directly involved in the RSGH pilot reported that they would like to continue using the programme and that they are planning on rolling it out to more patients in their care. Three out of the four clinicians also supported the plan for a trust wide roll out of the RSGH programme. The remaining one clinician felt it was too early to comment on both of these matters but is continuing to use RSGH and attend the steering group meetings to update the group on progress on implementation. To ensure a trust wide roll out is successful and for the RSGH programme to be sustainable, the project team have agreed on several recommendations as detailed in 12.13 of this document.

RSGH has proved to be an interesting pilot which has involved some hard work and determination on the part of the lead clinicians and good engagement from the transition steering group. There have been some challenges in implementing the new paperwork, however, throughout the project, the lead clinicians have been positive about developing their transition services and believe that a transition framework, such as RSGH would benefit their patients in the long term.

7  **OUH NETWORK TRANSITION NURSE PROJECT AIMS:**

The OUH Network Transition Nurse’s full end of project report can be found in appendix 5 and in the embedded document below:

7.1  **TO DEVELOP AN EDUCATIONAL PROGRAMME SUPPORTING IMPLEMENTATION OF READY, STEADY, GO, HELLO**

**Method:**
3x power point presentations around transition, an introduction to and advice on implementing the RSGH programme. Developed with the advice of the TVSCN and Southampton teams.

**Progress:**
This piece of work is now complete. To ensure the education programme can be taken forward, a ‘Train the Trainer’ presentation has been added to the transition toolkit.

7.2  **TO DEVELOP EDUCATIONAL MATERIALS TO SUPPORT RSGH AND TRANSITION SERVICE DEVELOPMENT**

**Method:**
A number of documents were developed to support trusts to develop transition services with the advice of the TVSCN and Southampton teams. Educational material included:
• 3x power point presentations around transition, an introduction to and advice on implementing the RSGH programme.
• Health and Social Care signposting resource: Local and national contacts provided to assist both clinicians with giving advice and to provide a resource for the HPs to give to young people.
• Frequently Asked Questions: RSGH Programme.
• Survey monkey questionnaire: This was not used during the project, but it has been developed and is available for use, if felt appropriate by the TVSCN transition best practice group. The idea behind this questionnaire was to get a snap shot response from young people immediately after being introduced to the ready steady go programme OUH Transition of Young People Intranet Page: this is a central resource for clinicians within the OUH trust to obtain vital information about transition and the RSGH programme http://ouh.oxnet.nhs.uk/Transition/Pages/Default.aspx

Progress:
This is now complete. The documents have been included in the transition toolkit and are available on the TVSCN website http://tvscn.nhs.uk/networks/maternity-and-childrens/children/transition-children-adult-health-services/ and on the OUH intranet site. They were promoted at the TVSCN transition event in December, 2015 and were included in the RSGH teaching sessions that were delivered across the Thames Valley.

7.3 TO ROLL OUT EDUCATIONAL SESSIONS IN ALL THE ACUTE TRUSTS ACROSS THE THAMES VALLEY

Method:
An invitation was sent to clinicians to attend training sessions on transition and the RSGH programme in July 2015 to four trusts within the Thames Valley: Oxford, Buckinghamshire (Bucks), Frimley health (Wexham Park) and Milton Keynes

Progress:
This element of the project is now complete. The response to the offer was very positive:
• The OUH Network – 15 training sessions delivered and direct contact was received from 24 clinicians from a range of specialties across paediatric and adult services.
• Wexham Park – 3 training sessions were delivered at Wexham Park and direct contact was received from 7 clinicians.
• Buckinghamshire Health Trust – 1 training session was delivered in the acute trust and 2 sessions have been delivered to community teams as a result of direct requests from 5 clinicians both within the acute trust and the community setting.
• Milton Keynes – 1 session was delivered at Milton Keynes and direct contact was received from 5 clinicians
8 Discussion

This has been a successful project and all the aims have now been achieved. Areas for further improvement have been identified (see section 9). It should be noted that the significant improvements seen at RBFT have been a direct result of having a dedicated resource in place to oversee transition service management. It is suggested that commissioners need to consider how hospitals in the region will be able to comply with the NICE (2016) guideline which states that providers should allocate a named transition worker for young people with long term conditions, who can support the young person and manage the administration process of their transition. In order to embed RSGH and ensure further improvement in transition services, this is a key consideration for the commissioners in the Thames Valley and Milton Keynes.

9 TVSCN Transition Project: Phase 2 (January 2016-March 2017)

9.1 Phase 2 Overview:

Phase 2 of the TVSCN Transitions Project will begin in March 2016 and last for one year. The aims of this phase of the project are, firstly, to ensure the continuation and embedding of the work carried out in the Royal Berkshire NHS Foundation Trust (RBFT) Transition Project (Jan 2015-16), which was to produce a more structured, coordinated and developmentally appropriate approach for young people moving from children’s to adult’s healthcare provision by piloting the ‘Ready Steady Go’ programme. Secondly, to continue the strategic work undertaken in the TVSCN transition project (March 2015-December 2015) to
support acute trusts across the Thames Valley and Milton Keynes to develop their transition services and implement ‘Ready Steady Go’ in their organizations. Finally, the Network Transition Nurse will collaborate with Diabetes and CAMHS networks to ensure best practice is shared in order to ensure a standardised approach to transition across the region.

9.2 SUMMARY OF AIMS:

1. Royal Berkshire hospital:
   - Pilot evaluation report (February 2016)
   - Continue to improve transition by embedding RSG in the existing specialities and ensure the use of a transition framework across the Trust (as agreed by the RBFT Transitions Steering Group) and ensure compliance with the transition policy across the Trust
   - Evaluate the impact of RSG based on patient experience by March 2017

2. Provider Trusts in Thames Valley and Milton Keynes
   - Each trust (Wexham Park, Milton Keynes, Stoke Mandeville and Oxford University Hospitals) will be offered support from the Network Transition Nurse. This support will include:
     - Advice on setting up a Trust Transition Steering Group / support existing transition steering groups / identify if existing Trust committees have transition as part of their annual work plan
       - advice on Terms of Reference
       - advice on membership
       - advice on transition strategy including the need to identify an executive lead for transition
       - attend meetings when required to share experiences from RBFT and from across the TVSCN
     - Supporting Trusts to develop their Trust Transition Policy
       - review any existing transition policy and advise if additional elements need to be included to comply with NICE Guidelines, SEND Reform and The Care Act
       - provide RBFT Transition Policy and Guidelines and support with adaptation of policy where needed
     - Support the implementation of RSG
       - provide a ‘RSG train the trainer’ session for steering group members to roll out to colleagues
       - deliver RSG training sessions as directed by the steering group (within the allocated time per month)

3. Thames Valley Strategic Clinical Network
   - End of year project report (March 2016)
   - Collaborate with regional CYP diabetes network to share best practice to ensure a standardised approach to transition
   - Collaborate with CAMHS / TV CYP Network for Mental Health and Wellbeing to share best practice to ensure a standardised approach to transition
   - Inform Commissioners through the TV Children and Maternity Commissioners managers group of the progress to inform their commissioning intentions for children and young people
The Children’s TVSCN quality improvement lead will be working with the Network appointed Transition nurse hosted at RBFT to achieve the aims above. At the end of this transition project in March 2017, there should be a standardised approach to providing effective transition from children to adult services. By building on the nationally respected work on the ‘Ready Stead Go’ programme undertaken by colleagues in Southampton it is believed that this project could be highly successful and create a model that could be replicated nationally. It is believed that an effective transition process which supports young people is associated with significant financial savings in the longer term.

Care Quality Commission (2014). *From the Pond into the Sea*. London: CQC


McDonagh, J. Viner, R. (2006) Lost in transition? Between Paediatric and adult services


Viner R (1999) *Transition from paediatric to adult care. Bridging the gap or passing the buck?* Archives of Disabilities in Childhood, 81, pp.271-275.

### Appendix 1: Thames Valley Best Practice Transition Pathway

**Generic Transition Pathway (for Young People with Long Term Conditions)**  
A Guide for Professionals  
(for "Ready Steady Go" users and non-users)

<table>
<thead>
<tr>
<th>'Ready Steady Go' specific actions</th>
<th>Actions for all Professionals</th>
<th>Actions for Health Professionals</th>
</tr>
</thead>
</table>
| Complete 'Ready' Questionnaire with young person over 2 years  
Note any actions / areas for development on Transition Plan  
Store questionnaire and transition plan in hospital / handheld notes. Provide copy for young person | 'READY'  
AGE 11-13  
Introduce the concept of transition and preparing for adulthood  
Use a holistic approach to transition, considering all aspects of the YP life | Introduce the concept of transition and learning more about their health condition  
Provide copy of your service’s transition pathway  
Flag ‘in transition’ on electronic patient record (if option is available) |
| Complete 'Steady' Questionnaire with young person over 2 years  
Note any actions / areas for development on Transition Plan  
Store questionnaire and transition plan in hospital / handheld notes. Provide copy for young person | 'STEADY'  
AGE 14-16  
Support the YP to develop their knowledge and skills  
Use a holistic approach to transition, considering all aspects of the YP life | Discuss the YP understanding of transition and their medical condition  
Provide Mental Capacity Act leaflet (where appropriate)  
Ensure ‘in transition’ is on flagged EPR (if option is available)  
Provide ‘signposting’ document when appropriate |
| Complete 'Go' Questionnaire with young person over 2 years  
Note any actions / areas for development on Transition Plan  
Store questionnaire and transition plan in hospital / handheld notes. Provide copy for young person | GO  
AGE 16-18  
Ensure knowledge and skills are embedded  
Discuss transition plans and timescales, consider others services accessed by YP | Discussion about transition plans and timescales, consider others services accessed by YP  
Consultant to ensure DNACPR/ACP documentation is changed onto adult forms (if appropriate)  
Note any specific transition instruction in comments box on ‘in transition’ on EPR (if option is available)  
Provide ‘signposting’ document when appropriate |
| Complete 'Hello' Questionnaire  
Note any actions / areas for development on Hello Transition Plan  
Store questionnaire and transition plan in hospital / handheld notes. Provide copy for young person | TRANSFER MEETING / CLINIC  
AGE 16-18  
OR  
TRANSFERRING CARE TO ADULT SERVICES LETTER  
AGE 16-18  
OR  
TRANSFERING CARE TO GP LETTER  
AGE 16-18  
OR  
DISCHARGE FROM SERVICES LETTER  
AGE 16-18 | Consider follow up arrangements for patient if they fail to engage (see local policy)  
Consultant to review DNACPR / ACP forms and add their own name (if appropriate)  
Remove ‘in transition’ flag on electronic patient record (if option is available)  
Consider the need for IMCA involvement when making decisions |

*Based on "READY STEADY GO" created by Dr. A. Nagra and the Southampton Children’s Hospital Transition Steering Group. Pathway developed by Polly Schofield (Lead Nurse for Transition Thames Valley Strategic Clinical Network). Approved for use by the TVSCN Transition Task and Finish Group, November 2015.*
<table>
<thead>
<tr>
<th>Action</th>
<th>Who is responsible</th>
<th>Deadline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify transition champions in acute trusts in the Thames Valley and Milton Keynes</td>
<td>Network Transition Nurse / TVSCN Quality Improvement Lead</td>
<td>January 2016</td>
</tr>
<tr>
<td>Champions to update the group on progress of, and support needed with:</td>
<td>Transition Champions</td>
<td>Every meeting</td>
</tr>
<tr>
<td>- Trust transition Steering groups development</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Trust transition policy development</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- RSG implementation and progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identify the key priorities for the working group to address within the context of the NICE Guidelines for Transition (Draft 2015, anticipated date of publication, February 2016)</td>
<td>All</td>
<td>April 2016</td>
</tr>
<tr>
<td>Share experiences of using RSG and keep a lessons learned log</td>
<td>All</td>
<td>Every meeting</td>
</tr>
<tr>
<td>Develop a RSG user guide for clinicians, based on the lessons learned log</td>
<td>All</td>
<td>March 2017</td>
</tr>
<tr>
<td>Agree a strategy for obtaining patient and parent views regarding the impact of RSG</td>
<td>All</td>
<td>April 2016</td>
</tr>
<tr>
<td>Providing advice and recommendations to commissioners (NHS England, Clinical Commissioning Groups and Local Authorities) via the TVSCN Steering Group</td>
<td>Network Transition Nurse / TVSCN Quality Improvement Lead</td>
<td>Quarterly</td>
</tr>
</tbody>
</table>
## Areas of concern: Comments from young people and parents (Post–transition Survey)

<table>
<thead>
<tr>
<th>Adult ward / OP environments</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 The adult wards are unfamiliar and not set up for teenagers</td>
<td></td>
</tr>
<tr>
<td>2 Frightening environment in the adult wards</td>
<td></td>
</tr>
<tr>
<td>3 Old people can be scary</td>
<td></td>
</tr>
<tr>
<td>4 I was worried the adult wards may be too noisy for XXX</td>
<td></td>
</tr>
<tr>
<td>5 I don’t think adult services are as caring</td>
<td></td>
</tr>
<tr>
<td>6 I don’t know how self-advocacy will be encouraged in an unfamiliar, busy environment</td>
<td></td>
</tr>
<tr>
<td>7 I have found there are different consultants at every appointment in adult service and XXX has never seen the same doctor twice</td>
<td></td>
</tr>
<tr>
<td><strong>Transfer clinics</strong></td>
<td></td>
</tr>
<tr>
<td>8 We did not have enough joint clinics with adults and paediatric consultants</td>
<td></td>
</tr>
<tr>
<td>9 XXX was transferred to adults too young (16) without support or proper planning</td>
<td></td>
</tr>
<tr>
<td>10 There was no agreed plan in place for XXX</td>
<td></td>
</tr>
<tr>
<td><strong>Information giving</strong></td>
<td></td>
</tr>
<tr>
<td>11 We needed more useful and practical information from the hospital about transition</td>
<td></td>
</tr>
<tr>
<td>12 It would have been good if children’s services could have signposted us to available services post 18</td>
<td></td>
</tr>
<tr>
<td>13 There was no clear pathway and who XXX would be referred to post transition</td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td>14 There is uncertainty about the future, we don’t know who XXX’s doctor will be and how often we will get to see them</td>
<td></td>
</tr>
<tr>
<td>15 We were worried about changes to funding of other health services such as OT</td>
<td></td>
</tr>
<tr>
<td>16 We were confused about how other services were going to change over to adults and what we would have to do, for example OT and physio</td>
<td></td>
</tr>
<tr>
<td>17 I do not get enough regular appointments in the adult service</td>
<td></td>
</tr>
<tr>
<td>18 There was no transition input from health (in overall transition process)</td>
<td></td>
</tr>
<tr>
<td>19 All health services need to have a transition plan</td>
<td></td>
</tr>
</tbody>
</table>
14.1 **PROJECT OVERVIEW**

In December 2014, a Lead Nurse for Transition was appointed at the Royal Berkshire NHS Foundation Trust (RBFT) to carry out a 12 month pilot of the nationally recognized transition programme ‘Ready Steady Go’ in 2 cohorts of patients; diabetes and neurodisability. The post was funded by the Thames Valley Strategic Clinical Network (TVSCN) and formed part of a Thames Valley wide project to develop transition services for young people with long term conditions. Each of the four clinicians directly involved in the pilot were given an evaluation form at the end of the year (evaluation summary can be found in appendix 1). This document is the final write up of the pilot project which includes the lessons learned and makes recommendations for a trust wide roll out.

14.2 ‘READY STEADY GO’ AND ‘HELLO TO ADULT SERVICES’

‘Ready Steady Go’ and the accompanying document, ‘Hello to Adult Services’ are generic transition programmes for young people with a long term condition aged 11+ years which was developed at the University Hospital Southampton. In this document, the acronym ‘RSGH’ refers to the entire ‘Ready Steady Go’ programme and the accompanying document, ‘Hello to Adult Services’. RSGH is a structured, but where necessary adaptable, transition programme which can be used across all sub-specialties. A key principle throughout RSGH is ‘empowering’ the young person to take control of their lives and equipping them with the necessary skills and knowledge to manage their own healthcare confidently and successfully in both paediatric and adult services. This is initiated through the completion of a series of questionnaires. The questions are deliberately broad providing the opportunity for the healthcare professional to ask targeted questions specific to their condition. The answers are used as a basis for starting discussion and the questionnaires are designed to prompt appropriate engagement over potentially difficult issues such as sex and psychosocial concerns. Any issues which may arise are carefully addressed prior to transfer to adult services.

The aim of RSGH is that the young person will be able to manage their healthcare successfully, not just in their local adult service but in any adult service across the country - whether or not they have previously met the adult physician or GP to whom their care is transferred. Where the young person has learning difficulties the carer works through the RSGH programme with the young person engaging as much as possible.

14.3 **RSG / HELLO DOCUMENTS**

**Transition: Moving to Adulthood leaflet:**

This leaflet can be given out to young people and their parents from the age of 11 to explain the process and the importance of preparation for adulthood:
**Young Person’s Questionnaires:**
There are 3 questionnaires for the young person in the ‘Ready Steady Go’ stage and each one can be completed over a period of 2 years in paediatrics, gradually increasing the young person’s knowledge and skills. There is one final questionnaire (Hello) which should be used once the young person has reached adult services:

- ‘Ready’ Age 11-13
- ‘Steady’ Age 14-15
- ‘Go’ Age 16-18
- ‘Hello to adult services’ Age 16+

**Parents’ Questionnaires:**
There are 2 questionnaires for parents to complete, to help prepare them for their child’s transition to adulthood; one to be completed in paediatrics, and the other to be completed in adult services:

- Parents Questionnaire 1
- Parents Questionnaire 2

**Transition Plans:**
There are 2 transition plans, one for paediatrics and one for adults. This is where targets and progress can be documented:

- Transition Plan 1
- Transition Plan 2
14.4 DEFINITIONS

- **Transition**
  The process of preparing, planning and moving from children’s to adult health services.

- **Transition Programme**
  A planned and documented process of developing the young person and their parent/carer’s knowledge and skills in preparation for adulthood.

- **Transfer Clinic**
  The transfer of a patient from their Paediatric consultant to an adult consultant during a joint clinic appointment.

- **Parent / carer**
  A mother, father, legal guardian, close relative or close friend who are adults (older than 18 years) and who have been closely involved in caring for children prior to admission to hospital.

- **Electronic patient Record (EPR)**
  Component of the Royal Berkshire NHS Foundation Trust computer system which records the patient’s name, home address, date of birth and each admission, discharge and contact with the outpatient department.

- **Special Educational Needs and Disability (SEND)**
  A child or young person has SEND if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.

- **Lead Clinician**
  The clinician responsible for managing the RSGH pilot within each specialty.

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14.5 IDENTIFICATION OF PILOT COHORTS:

A transition steering group was set up by the project lead and all paediatric and adult specialty leads at the RBFT were sent Terms of Reference for the group and were invited to attend an initial scoping meeting. Two cohorts of patients were identified by the transitions steering group, who it was felt would benefit from the RSGH pilot:

1. Neurodisability
2. Diabetes

These two cohorts had lead clinicians who had a drive to develop their transition services and were keen to pilot the programme in their areas.

**Training**

Informal training on RSGH was given to the lead clinicians before commencing the pilot. As the clinicians began to use the questionnaires in clinic and they, and the project lead became more familiar with the programme, a formal training session was developed by the project lead, based on the lessons learned. This training session and was delivered to clinicians outside of the cohort groups on request.

**Document ordering**

An external print company was identified by the RBFT procurement department. RSGH documents were ordered under each specialties’ cost centers. The number of documents that were ordered for each cohort was based on the patient data analysis carried out pre-project. The ordering process was managed by the project lead initially, but in the pilot evaluation, teams identified that in order to make this sustainable, they needed to nominate a member of their team who would be responsible for replenishing stocks.
Identification of patients in each cohort
The project lead requested data from RBFT informatics in order to identify the names of young people aged 11-19, for each cohort. This data was taken from the Electronic Patient Record system (EPR). The data was entered onto a spreadsheet by the project lead and shared with the lead clinicians in order to facilitate the management of patients on the programme. The spreadsheets were managed by the lead clinicians in each area.

<table>
<thead>
<tr>
<th>HospNo (MRN)</th>
<th>Age</th>
<th>DOB</th>
<th>Surname</th>
<th>Forename</th>
<th>Ready Date</th>
<th>Steady Date</th>
<th>Go Date</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Xxxxxx</td>
<td>14</td>
<td>xx/xx/xxxx</td>
<td>Xxxxxx</td>
<td>Xxxxxx</td>
<td>n/a</td>
<td>Feb-15</td>
<td>Feb-17</td>
<td></td>
</tr>
</tbody>
</table>

Issues with data collection
The data was difficult to obtain and often the information that came from informatics was not complete. For example, the data for neurodisability did not include some young people that were known to clinicians. These were added individually but it raised concerns that not all young people with neurodisability treated at the RBFT were captured on the data request. When the diabetes data was analyzed, the number of patients did not align with the data held by the team. The paediatric diabetes team use a different electronic patient record (‘Twinkle’). Again, this raised concerns that not all young people with diabetes treated at the RBFT were captured on the data request and subsequent spreadsheet. Management of the spreadsheet was time consuming for some clinicians who found it easier to manage their patient using paper record and hand held files. There were sometimes issues with different people accessing the spreadsheet; however, this was mitigated by holding the document on the paediatrics shared drive.

As a result of the project there is now functionality to add patients onto a transition database on EPR. This involves clinicians adding ‘In Transition’ to individual patient’s records and adding specific notes and instructions to colleagues. A report can be run intermittently to allow for better tracking and ensure timely transfer clinic planning.

14.6 PROCESS – DELIVERING THE RSGH PROGRAMME
The guidance that came from the RSGH programme developers at the University Southampton Hospital states that there is ‘no one way’ to deliver the programme. Each lead clinician at the RBFT managed the delivery of the programme in a way that suited their teams and the management of their patients. This management was reviewed at steering group meetings and discussed with the project lead on an individual basis throughout the year. As this was an ongoing learning process, the delivery method was developed as clinicians became more familiar with the programme.
14.6.1 Paediatric Diabetes – Ready Steady Go

<table>
<thead>
<tr>
<th>Lead Professional:</th>
<th>Paediatric Diabetes Specialist Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of young people on RSGH:</td>
<td>15</td>
</tr>
<tr>
<td>Date of commencing the pilot:</td>
<td>January 2015</td>
</tr>
</tbody>
</table>

**Process in Paediatric Diabetes**

In January 2015, the Paediatric Diabetes Specialist Nurse (PDSN) identified a group of patients to take part in the pilot. The RSGH leaflet was given out to the young people and the programme was explained to the young person. The PDSN carries hand held notes with the RSGH documents for each of her patients. The PDSN goes through the questionnaires with the young person during their home / school visits and during the Nurse Led Clinics and any actions or concerns are documented on the transition plan. If there are any particular issues that need to be addressed by the medical team, they are communicated with the consultant in the Multidisciplinary Team meeting. Before the final transfer to adult services meeting, the RSGH documents are copied and put in the hospital notes. For the fifteen young people accessing the programme, RSGH now forms part of the diabetes structured education plan which is offered by the team at the RBFT.

**Issues that arose in Paediatric Diabetes**

**Time**

Clinic time is limited and is already taken up with medical management. This programme can form part of the patient assessment, and as already mentioned, can form part of the structured education programme. However, clinicians reported that, ideally, there needs to be additional clinic time to go through the questionnaires thoroughly. The Lead clinician also reported that patients would benefit from seeing PDSNs to go through the RSGH questionnaire before or after their consultant appointment in the hospital. This would reduce the amount of appointments the young person would have to attend and would allow for issues to be addressed in one visit. In order for this to happen, the PDSNs need access to a clinic room. This has been taken forward as an action by the lead clinician.

**Location of the RSGH Documents**

As the PDSN carries the RSGH documents in the handheld notes, there is a risk that the consultant will not have access to them during their consultant clinic appointments. This was highlighted as an area of concern that needed to be addressed in order for the RSGH programme to be sustainable. As a result of this concern, changes have been made to the diabetes electronic patient record, Twinkle. Twinkle can now show where a patient is on the programme and comments can be added regarding their transition. This information can be seen any member of the Multidisciplinary Team who have access to Twinkle.

**No electronic copy**

There is not currently an electronic version of RSGH. This limits the way young people can access the programme and there is a risk that the completed paper copies will not be brought into clinic by the young person or that they might not be filed correctly. The Diabetes Transition Service Specification (December 2015) highlights the importance of using technology as a means of continuing to engage young people with health professionals and encouraging medication adherence. Clinicians raised the
need for an online version of RSGH as a key factor in ensuring patient engagement with and in sustaining
the programme in the long term.

**Appropriateness of RSGH questions**
The questionnaires are generic, and as such, the lead clinician found that the questions alone did not
address the in-depth disease knowledge and management needed in diabetes. Although the
questionnaires were not changed, the RSGH questions were adapted by the clinician during discussions
with the young person to ensure they related to diabetes and were individualized to the specific needs of
their patients

**14.6.2 Adult Diabetes –‘Hello’**

<table>
<thead>
<tr>
<th>Lead Professional:</th>
<th>Adult Diabetes Specialist Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of young people on the RSGH:</td>
<td>10</td>
</tr>
<tr>
<td>Date of commencing the pilot:</td>
<td>June 2015</td>
</tr>
</tbody>
</table>

**Process**
Due to issues with documentation ordering, the adult diabetes team did not start using the Hello
questionnaires until June 2015, so the process is still relatively new. The consultant, clinic nurse and
Diabetes Specialist Nurse are all involved with completing the ‘Hello’ questionnaire with patients. The
young person with diabetes will either be in transition from paediatrics or they will be a new young
patient in the adult clinic. The completed patients’ questionnaires are filed in the medical records and if
the parent is present, the completed parent questionnaire it is also filed in the young person’s records. If
any issues or concerns are identified, appropriate referrals are made to other healthcare professionals e.g.
psychologist or dietitian.

**Issues that arose in Adult Diabetes**
The lead clinician reported very similar issues in their evaluation, as identified by the Paediatric lead. The
lessons learned in paediatrics will also apply to adult diabetes

**14.6.3 Paediatric Neurodisability – ‘Ready Steady Go’**

<table>
<thead>
<tr>
<th>Lead Professional:</th>
<th>Community Paediatric Consultant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of young people on RSGH:</td>
<td>30</td>
</tr>
<tr>
<td>Date of commencing the pilot:</td>
<td>January 2015</td>
</tr>
</tbody>
</table>

**Process**
The lead clinician identifies patients who will be started on the RSGH programme and there is an initial
discussion in their clinic appointment. The information leaflet and the first questionnaire is then either
given to them to take away, or they are sent out in the post after the appointment. The questionnaires
are sometimes left out for the young people in reception, and they are asked to fill them in before they
see the doctor. The questionnaires are reviewed with the consultant in their next clinic and any issues are
addressed and actions noted. Copies of the questionnaires are held in the patient’s hospital notes. If a
RSGH stage has not been completed, the consultant will start with that questionnaire again at the next
clinic appointment.
Issues that arose in Paediatric Neurodisability:

Administration
The current process relies on the lead clinician ensuring the administration team know to include the leaflet and questionnaires in the clinic letters. It also relies on the receptionist to give out the questionnaire and there being time for the patient / parent to fill it out before their appointment. The lead clinician has been managing this process so far, but in order to ensure sustainability, there needs to be a more robust process for the administration of the RSGH documents.

Time
As with diabetes, clinic time for this cohort of patients is limited and is already taken up with complex medical issues. The lead clinician reported that ideally, there needs to be additional clinic time to go through the questionnaires thoroughly. However, she reported that the programme sometimes helped to focus clinic appointments and helped to address difficult issues.

RSGH Lead professional
Due to their complex needs, young people with neurodisability are likely to be accessing a number of health services. There have been discussions about whether the community pediatrician should lead the RSGH programme, or whether other health professionals can also use the document as way of assessing the transition needs of their patients. In order to reduce confusion during the pilot, it was decided that the consultant would lead on it, but would communicate specific aspects of the programme with relevant professionals. This would need to be discussed further if the programme was to be rolled out as there will often be a ‘cross over’ of professionals for these patients.

Location of RSGH Documents
There is no electronic version of RSGH so, currently, the document is held in the patients’ hospital notes. This poses a risk that the health transition plans may not be accessible by other relevant professionals, e.g. children’s community nurses, school nurses, therapists. This was highlighted by clinicians as is an important issue to overcome as one of the aims of the RSGH programme is to reduce the need for the young person and their parents to repeat the same thing to lots of different professionals. Currently, transition issues / arrangements are documented in the young person’s clinic letter and the relevant professional is copied into the clinic letter with the parent’s consent.

No electronic copy
As with diabetes, this was highlighted as a problem. If there was to be a trust wide roll out, there is likely to be more than one professional using the document with a young person with complex needs. If there is no electronic copy, there is a risk of duplication which would be frustrating for the patient and their family as they will have to give the same information multiple times. Currently this is being managed by ensuring there in one professional leading on it for each patient.

 Appropriateness of the questions
In the pilot evaluation questionnaires, clinicians highlighted that some of the questions in the RSGH programme are inappropriate for young people with a severe learning disability and or a life limiting condition, as the ultimate outcome from the programme is for them to become as independent as possible in adulthood. This is not going to be the case for many of these young people and often the questions, as they stand, are not suitable. Clinicians however, have overcome this by ensuring that they go through the questionnaire together with the young person and their parents and adapt the questions
to meet their individual needs. By doing this, they still address their transitional care, whilst being sympathetic to the challenges that the young person and their family may be facing in the future. This approach requires skillful conversations led by the lead clinician and a common understanding with the young person and parent that their transition is about ‘preparation for adulthood’ as opposed to becoming an independent adult.

**Communicating transition plans with other agencies**

If the young person has an Education Health Care Plan (EHCP) they will have an ‘education transition plan’ which is developed when they are aged 14. This is led by the school but requires input from social care and health. It is important the RBFT have a way of supporting these plans and ensuring the schools are aware that the young person is on the RSGH programme and what arrangements are in place for their health transition. There are ongoing conversations between the RBFT and local schools as to how this can be achieved. The project lead has delivered training on the use of RSGH at the RBFT and the transition pathways to the ‘Pan-Berkshire Special Educational Needs (SEND) Reform Joint Implementation Transitions Group’. The local Authority in Reading are considering promoting the use of RSGH within schools to ensure a consistent approach to transition planning for young people with SEND.

**14.6.4 Adult Neurodisability – ‘Hello’**

<table>
<thead>
<tr>
<th>Lead Professional:</th>
<th>Adult Neurorehabilitation Consultant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of young people on RSGH:</td>
<td>10</td>
</tr>
<tr>
<td>Date of commencing the pilot:</td>
<td>January 2015</td>
</tr>
</tbody>
</table>

**Process**

The concept of the ‘Hello’ programme is first introduced in the transfer clinic and the Hello questionnaire is sent out with their clinic letters. Some of these young people may already be on the RSGH programme so they and their families are likely to have some understanding of it. At their first adult clinic appointment, the lead clinician goes through the questionnaires and any actions or areas of concern are noted. The completed questionnaires are held in the patients hospital records and will be readdressed at each future clinic appointment.

**Issues that arose in Adult Neurodisability**

The lead clinician reported very similar issues as identified by the paediatric lead. The lessons learned in paediatrics will also apply to adult neurodisability.

**14.7 Cost Implications**

**Printing**

A printer was sourced by the RBFT procurement department and the cost of printing can be seen in table 1 below. The project lead discussed the cost of printing with the procurement department but the cost cannot be lowered unless the RBFT order the documents in bulk (1000+ copies at a time). If the RBFT were to propose a trust-wide roll out, the printing costs may reduce significantly. It should be noted that the cost of the trifold ‘Transition Plan’ significantly increases the cost per patient. A breakdown of the printing costs can be found in table 3.
Table 3: RSGH Printing Costs

<table>
<thead>
<tr>
<th>RSGo (Paediatrics age 11-16)</th>
<th>Size</th>
<th>No. needed per patient</th>
<th>No. in pack</th>
<th>Cost</th>
<th>Cost/patient for complete 5 year RSG programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>RSG Moving into adult care</td>
<td>A5 6pp roll fold 4/4</td>
<td>1</td>
<td>50</td>
<td>£62.50</td>
<td>£1.25</td>
</tr>
<tr>
<td>RSG Young Persons Transition Plan</td>
<td>A4 6pp Trifold 4/4</td>
<td>1</td>
<td>50</td>
<td>£330.0</td>
<td>£6.60</td>
</tr>
<tr>
<td>RSG Parent/Carer Transition Plan</td>
<td>A4 2pp 4/4</td>
<td>1</td>
<td>50</td>
<td>£25.00</td>
<td>£0.50</td>
</tr>
<tr>
<td>RSG Getting Ready Document</td>
<td>A4 2pp 4/4</td>
<td>1</td>
<td>50</td>
<td>£25.00</td>
<td>£0.50</td>
</tr>
<tr>
<td>RSG Steady document</td>
<td>A4 2pp 4/4</td>
<td>1</td>
<td>50</td>
<td>£25.00</td>
<td>£0.50</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
<td>£9.85</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hello (Adult services 16-18)</th>
<th>Size</th>
<th>No. needed per patient</th>
<th>No. in pack</th>
<th>Cost</th>
<th>Cost/patient for ‘Hello’ programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>RSG Hello to Adult Services transition plan</td>
<td>A4 6pp roll fold 4/4</td>
<td>1</td>
<td>50</td>
<td>£330.0</td>
<td>£6.60</td>
</tr>
<tr>
<td>RSG Hello to adult services Parents / Carers plan</td>
<td>A4 2pp 4/4</td>
<td>1</td>
<td>50</td>
<td>£25.00</td>
<td>£0.50</td>
</tr>
<tr>
<td>RSG Hello to adult services Hello</td>
<td>A4 2pp 4/4</td>
<td>1</td>
<td>50</td>
<td>£25.00</td>
<td>£0.50</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
<td>£7.60</td>
<td></td>
</tr>
</tbody>
</table>

14.8 Using the RSG / Hello Documents

Transition to Adulthood leaflet

Due the administration issues already mentioned, the leaflet was often not given out prior to introducing the programme to young people. The guidance from Southampton University Hospital, is that the leaflet needs to be given to young person and parents before commencing the RSGH programme. This will help them to understand the reason for starting the programme and allow time for them to ask the clinician questions about it and raise any concerns in a timely manner. However, there were reported incidences at RBFT where the leaflet was sent out with a clinic letter and this caused the young person and their family distress. Sometimes, particularly with young people with complex needs and or a life limiting condition, there needed to be face to face discussion about the programme and what this means for young people, because the leaflet, is written for young people where the expectation is that they will become independent adults. As the leaflet is part of the RSGH programme, it does not have specific information about transition services at the RBFT. It is also not currently available in ‘easy read’ or other languages.
RSG/Hello Young person’s questionnaires
The clinicians reported that they found the questionnaire easy to use and that they facilitated a holistic assessment of the young person, however, the questions were not always appropriate. As previously mentioned the questions may at times need to be delivered in a sensitive way and any specialty wanting to adopt the programme will be educated in this before implementing it in their areas.

Parent / carer’s questionnaire
This has proven to be a useful document, especially in ‘Hello to adult services’ where the parent / carer may need some encouragement to let the young person advocate for themselves. This document can be re-issued to the parent throughout the RSGH programme.

Transition plan
The evaluation forms highlighted that there have been some issues with this document. The headings do not correspond with the headings on the questionnaires which makes it more time consuming to transfer information across onto this document. The document is printed on an A4 ‘tri-fold’ which makes it difficult and time consuming to print out copies for patients. This can cause problems as there may be important information on the transition plan that the young person and their family need to take away with them. As mentioned in section 8 of this report, the size and shape of this document makes it significantly more expensive than the rest of the documents. This has caused a reluctance to re-order this element of the RSGH programme. Finally, there is limited space on the front of the document to add all the professionals involved in the young person’s care. A recent case study of a young person with neurodisability at RBFT found that she accessed 33 different services which all needed transition planning input from the community paediatrician. Currently, there is nowhere on the transition plan to document this type of information.

14.9 IMPACT ON CLINICAL PRACTICE
Impact on clinical time
As with any new document, there is a certain amount of time that is needed for the clinician to get used to using RSGH. During the pilot, it has been found that the impact on clinical time has reduced as some of the administration issues have been resolved and as the clinician gets used to using RSGH as part of their holistic assessment of their patients. However, clinicians reported that for the programme to be really effective, more time in clinic was needed to dedicate to transition planning.

Signposting Concerns
The RSGH programme addresses a variety of issues that may not ordinarily be discussed in clinic with the consultant. It is important to note the questions are designed to ‘start a conversation’ with the young person. It is not expected that the clinician would have all the answers, but in their capacity as the young person’s point of contact in health, they should be able to signpost the young person and or their parent/carer to an appropriate person or service. The project lead has contributed to the development of a signposting document which includes services available for advice and support in the Thames Valley. This is available as a download on the transitions page of the RBFT intranet.

Improved documentation
By the very nature of the RSGH programme, there is improved documentation of the transition process, adolescent issues and transition planning. It is important that this documentation is shared where appropriate with the young person, parents and other professionals involved in their care in order for it to have a real impact on the young person’s smooth transition into adulthood.
**14.10 Impact on Patient**

It is anticipated that the implementation of a transition programme will have a positive impact on the long term health outcomes for young people with a chronic condition. However, as the programme has only been piloted for one year it is not possible to assess the outcomes properly at the time of the report. Most of the young people will have only accessed one of the questionnaires once or twice as it can take up to two years to complete them. The feedback from the clinicians that they believe the RSGH programme will have a positive impact on their patients understanding of transition and their preparation for adulthood, but that it is too early to evaluate this properly.

The feedback that came from a pre-project patient survey (figure 6) indicated that young people and their families want the RBFT to have a clear plan for their transition and that communication between patient and clinician and communication between services should be improved.

The survey also highlighted that for many respondents transition planning did not start early, that there was not a key person to support them through transition, that there was not a written plan for transition and that the hospital did not consider their needs in a holistic way (figure 6). By the very nature of the RSGH programme, these concerns will be addressed and managed through the delivery of the questionnaires.

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**Figure 6: Pre-project Transition Survey – patient and family feedback**

“I didn’t know how often I was going to see my new doctor”

“There was no clear transition pathway, we didn’t know who (...) was going to be referred to”

“The hospital could have helped more with signposting us to other services that were available post-transition”
14.11 DISCUSSION

**Identifying Transition Champions**

Due to the issues already reported about encouraging engagement from clinicians and ensuring sustainability of the programme, the project team agreed that when planning a trust wide roll out, the project lead should try and identify a lead clinician or a ‘transition champion’ in each specialty. This will be done by making direct contact with the leads of each specialty and requesting a 15 minute meeting to discuss RSGH. Once the first contact with clinicians has been made, a member of the project team will deliver a 20 minute training session on RSGH in the relevant clinical governance meetings. The 20 minute RSGH training will include instruction on how to use the functionality on EPR that allows them to add patients in transition into a central database, and how to add specific instructions for every patient. Each of the transition champions will also be given a Transition Tracker spreadsheet which will assist them with identifying which stage young people are at on the programme and will help with an annual audit of RSGH compliance. The project lead has a number of free copies of the programme so every specialty can be given a starter pack and instructions on how to re-order.

The ‘transition champion’ will be responsible for promoting RSGH within their teams, establishing the re-ordering and administration processes and feeding back to the project lead on the progress with implementation. Identifying transition champions across the trust will ensure the RBFT are compliant with elements of the National Institute for Clinical Excellence (NICE) Guidelines for Transition (2016) which recommends that providers have transition key workers.

**Documentation**

As there is no way for the documents to be held electronically at the moment, the team agreed that the best solution to this was to keep them in the hospital or hand held notes and, wherever possible, copy the questionnaires and give copies to the young person and or their parent. The lack of an electronic version that could be accessed by the young person was of real concern to the lead clinicians, for the reasons already reported. As a result, the project lead has added ‘Electronic availability of RSGH’ as a work stream to the transitions project and will keep the steering group up to date on the available options.

**RSGH Lead Clinician**

In order to ensure there is no confusion with who is leading on the RSGH programme for young people who may be accessing a number of different services, the team agreed that the lead clinician will make it explicit in clinic letters that they have started the young person on RSGH, document any issues / targets / concerns and copy this letter to all the relevant professionals. The RSGH programme may have positive benefits for how the RBFT communicate transition arrangements with outside agencies, particularly when contributing to EHCP plans and the school transition meetings.

**Appropriateness of the RSGH Questions**

As previously reported, the RSGH questions could be considered to be inappropriate for some young people. The team agreed that the RSGH training session should include a slide on using a flexible, sensitive and individualized approach to using the questionnaires. For young people with a mild learning difficulty, the project lead has developed an ‘easy read’ RSGH questionnaire. This is available on the Trust intranet and in the paediatric clinic rooms.

In response to the comments made about the leaflet, the project lead will develop RBFT specific transition leaflet for young people and their families. The leaflet will include the Best Practice Transition
Pathway and an explanation of RSGH. There will also be an ‘easy read’ version for young people and parents / carers who have moderate learning difficulties.

**Transition Planning Document**

There were several concerns raised over the ‘Transition Plan’ which is used to document ongoing transition arrangements. In response to this, the project team have agreed that an alternative document be developed to capture this information in a more user-friendly format. It is hoped that this will encourage compliance with the programme. The document will be A3 in size, folded into an A4 folder. It will include the patient demographics, transition arrangements for all services accessed by the young person, the RSGH questions and a continuation sheet. The document would be held in the patient’s notes and would be continued in adult services.

**Transition Lead Nurse / Named Transition Worker**

The project was led by a nurse who was specifically employed 3 days a week to improve transition services across the trust. This post has now been reduced to 1 day a week until March 2017. This means that it is imperative that RSGH becomes embedded in the pilot groups in order for it to be sustainable in the long term. The clinicians did have concerns about the time it took to manage the administration process with RSGH and the time it took to complete the questionnaires in clinic. The NICE Guidelines (2016) recommend that providers should allocate a named transition worker for young people with long term conditions, who can support the young person and manage the administration process of their transition. In light of this, the RBFT should consider how this resource can be provided for young people with long term conditions.

**14.12 Conclusion**

The project team concluded that it was too early to fully evaluate the impact that the RSGH programme was having on their patients, but all believed it had potential to have positive outcomes for young people. The team agreed that a transition survey should be re-issued in January 2017 once the process has been embedded and young people have been able to fully access one of the programme stages. Three out of the four clinicians directly involved in the RSGH pilot reported that they would like to continue using the programme and that they are planning on rolling it out to more patients in their care. Three out of the four clinicians also supported the plan for a trust wide roll out of the RSGH programme. The remaining one clinician felt it was too early to comment on both of these matters but is continuing to use RSGH and attend the steering group meetings to update the group on progress on implementation. To ensure a trust wide roll out is successful and for the RSGH programme to be sustainable, the project team have agreed on several recommendations as detailed in section 12.13.

RSGH has proved to be an interesting pilot which has involved some hard work and determination on the part of the lead clinicians and good engagement from the transition steering group. There have been some challenges in implementing the new paperwork, however, throughout the project, the lead clinicians have been positive about developing their transition services and believe that a transition framework, such as RSGH would benefit their patients in the long term.

As already discussed, the RBFT need to consider how it will comply with the NICE (2016) guideline which states that providers should allocate a named transition worker for young people with long term conditions, who can support the young person and manage the administration process of their transition. In order to embed RSGH and ensure further improvement in transition services, this is a key consideration for the Trust.
<table>
<thead>
<tr>
<th>No.</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Identify a lead clinician or a ‘transition champion’ in each specialty.</td>
</tr>
<tr>
<td>2</td>
<td>Project Lead to deliver a 20 minute training session on RSGH in the relevant clinical governance meetings.</td>
</tr>
<tr>
<td>3</td>
<td>Transition Champions to ensure they add patients to RSGH Tracker spreadsheet</td>
</tr>
<tr>
<td>4</td>
<td>All clinician to ensure they add ‘In Transition’ to patients’ records</td>
</tr>
<tr>
<td>5</td>
<td>Wherever possible, photocopy the RSGH questionnaires and give copies to the young person and or their parent. File original in the hospital / handheld notes</td>
</tr>
<tr>
<td>6</td>
<td>Add works stream to transitions project: ‘Electronic availability of RSGH and keep the steering group up to date on available options</td>
</tr>
<tr>
<td>7</td>
<td>Ensure a representative from the administration teams are invited to steering group meetings.</td>
</tr>
<tr>
<td>8</td>
<td>Transition Champions to agree administration process with the whole team when implementing RSGH</td>
</tr>
<tr>
<td>9</td>
<td>Clinicians to make it explicit in clinic letters that they have started the young person on RSGH, issues / concerns / targets are documented and copied to all relevant professionals</td>
</tr>
<tr>
<td>10</td>
<td>RSGH training session to include using a flexible/ sensitive approach to using the questionnaire for young person with a severe learning disability and or a life limiting condition.</td>
</tr>
<tr>
<td>11</td>
<td>Develop RBFT specific transition leaflet for young person, including an ‘easy-read’ version</td>
</tr>
<tr>
<td>18</td>
<td>Develop a RBFT Transition A3 plan which has space to add all the professionals involved, track the young person’s transition progress and document actions.</td>
</tr>
<tr>
<td>19</td>
<td>Re-issue a transition survey to young people and their families in January 2017</td>
</tr>
</tbody>
</table>
RBFT need to consider how it will comply with the NICE (2016) guideline which states that providers should allocate a named transition worker for young people with long term conditions, who can support the young person and manage the administration process of their transition.

### 14.14 RSGH Pilot Evaluation Summary

#### Preparation and Administration

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>I received adequate training on RSG/Hello before starting the pilot</td>
<td>3/4</td>
<td>I am starting to put ‘in transition’ onto EPR but I prefer tracking it myself on a spreadsheet.</td>
</tr>
<tr>
<td>I understand how to re-order the RSG/Hello documents</td>
<td>3/4</td>
<td>Currently only 15 patients so I am aware of the all and what stage they are at. We use a different system in diabetes and will be tracking it on there in the future.</td>
</tr>
<tr>
<td>I use EPR to track and identify patients who are on the RSG/Hello programme</td>
<td>1/4</td>
<td>- Only if they are filed in the records- if the records are not available then the RSGH would not be completed.</td>
</tr>
<tr>
<td>My colleagues know where to access the completed RSG/Hello documents for each patient</td>
<td>3/4</td>
<td>- Only if they are filed in the records- if the records are not available then the RSGH would not be completed.</td>
</tr>
</tbody>
</table>

#### Ease of Use

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>The questions in the RSG/Hello documents are appropriate for my patients</td>
<td>0/4</td>
<td>- Rarely can the questions be asked without tailoring it to the individual needs of the patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Not many of my patient can access the programme independently</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Transition leaflet would be better if it explained the process at the RBFT</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Easy read leaflet needed</td>
</tr>
<tr>
<td>The RSG/Hello questionnaires (patient and carer questionnaires) were easy to use</td>
<td>3/4</td>
<td>- Difficult to use for young people with learning difficulties</td>
</tr>
<tr>
<td>The Transition Plan was easy to use</td>
<td>0/4</td>
<td>- Not enough space for all services accessed by young person</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Actions are duplicated – on the questionnaire and on the plan. One document add all the information on in one place would be useful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Time consuming to print and very</td>
</tr>
</tbody>
</table>
expensive!
- Clunky – does not match up with the questionnaires

<table>
<thead>
<tr>
<th>IMPACT ON CLINICAL PRACTICE</th>
<th>Strongly agree</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>The RSG/Hello programme will help communicate my patients’ transition arrangements with colleagues in RBFT</td>
<td>3/4</td>
<td>It should, in time as everyone gets used to using it</td>
</tr>
</tbody>
</table>
| Delivering the RSG/Hello programme requires additional clinic time and / or clinic preparation time | 3/4 | Yes, a significant amount of time
- Programme does not take long in terms of questionnaire but there is very little time to address the complex issues identified
- Yes, can do |
| Delivering the RSG/Hello programme has improved my documentation of adolescent issues | 3/4 | Still going through teething problems |
| Delivering the RSG/Hello programme has helped focus clinic appointments and address difficult issues | 3/4 | More signposting resources are needed when bringing up difficult issues. |

<table>
<thead>
<tr>
<th>IMPACT ON PATIENTS AN THEIR FAMILIES</th>
<th>Strongly agree</th>
<th>Comments</th>
</tr>
</thead>
</table>
| The RSG/Hello programme has benefitted my patients | 1/4 | Too early to say
- I think it is too early to comment on this |
| The RSG/Hello programme allowed my patients and their families to ask more questions about their transition to adulthood | 3/4 | |
| The RSG/Hello programme helped my patients and their families understand the transition process at the RBFT | 3/4 | |

<table>
<thead>
<tr>
<th>Cost effectiveness</th>
<th>Strongly agree</th>
<th>Comments</th>
</tr>
</thead>
</table>
| The RSG/Hello programme is cost effective: | 2/4 | Transition plan is very expensive
- Cannot comment of the ‘Hello’ element |
<p>| Cost per patient for complete 5 year RSG programme = £9.85 | |
| Cost per patient for ‘Hello’ programme = £7.60 | |</p>
<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like to continue using RSG/Hello in my area of practice</td>
<td>3/4</td>
<td>too early to make this decision</td>
</tr>
<tr>
<td>I would support a trust wide roll out of the RSG/Hello programme</td>
<td>3/4</td>
<td>too early to make this decision</td>
</tr>
<tr>
<td>Please state any further thoughts / comments / suggestions that would improve the delivery of the RSG/Hello programme:</td>
<td></td>
<td>- Development of a singular document through the whole process, whilst keeping the elements of the RSGH programme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Electronic version</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- RSGH App to improve young person’s access to the programme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Continued support and training available to all staff on RSGH and transition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Better engagement from medical staff</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- The programme is new to our team as the pilot began in November 2015. We need to continue and improve communication within our team. This will be discussed in our team meetings.</td>
</tr>
</tbody>
</table>
15.1 To develop an educational programme supporting implementation of Ready, Steady, Go

Method:
- 3x power point presentations around transition, an introduction to and advice on implementing the RSG programme. Developed with the advice of the TVSCN and Southampton teams.
- An invitation was sent to clinicians to attend training sessions on transition and the Ready Steady Go (RSG) programme in July 2015 to four trusts within the Thames Valley: Oxford, Buckinghamshire (Bucks), Frimley health (Wexham Park) and Milton Keynes

Outcome
The response was very positive:
- Oxford University Hospitals - 15 training sessions delivered and direct contact was received from twenty four clinicians from a range of specialties, disciplines and across the paediatric and adult services.
- Wexham Park - three training sessions delivered at Wexham Park and direct contact was received from seven clinicians.
- Buckinghamshire Health Trust – 1 training session was delivered in the acute trust and 2 sessions have been delivered to community teams as a result of direct requests from 5 clinicians.
- Milton Keynes – 1 session was delivered at Milton Keynes and direct contact was received from five clinicians.

The OUH Network Transition Nurse would have liked to progress at each trust with setting up a transition steering group and meet with the senior members of the paediatric teams but unfortunately this has proved difficult. It was therefore limited how far she could progress the overall impact and implementation of the Ready Steady Go transition programme, however she continued to do as much as possible within her limitations. She met with all clinicians and/or teams that made contact. She has also made each trust aware of her intentions to set up a steering group, and for her hosts Oxford, she recruited twelve clinicians to be part of this team. She also set up a transition intranet page as a central resource and put the work into setting up a young person’s website in collaboration with the media and communications team within the trust. She has developed a number of supportive documents to aid the implementation of the RSG programme and assist health professionals (HP) with signposting to local and national resources.

15.2 To develop educational materials related to transition
- 3x power point presentations around transition, an introduction to and advice on implementing the RSG programme. Developed with the advice of the TVSCN and Southampton team.
- Health and Social Care signposting resource: Local and national contacts provided to assist both HP with advice and providing a resource for the HPs to give to young people.
- Frequently Asked Questions: RSG Programme, questions that myself and Polly Schofield (Transition Project Nurse, Reading) have commonly been asked. Advice sought from Southampton team in answering of these questions.
- Survey monkey questionnaire: This was not used by the project, but developed and available for use if felt suitable, see link. The idea behind this questionnaire was to get a snap shot response from
young people immediately after being introduced to the ready steady go programme. This will roll out educational sessions in all the acute trusts across the Thames Valley.

Figure 6: Location of training sessions attended across the Thames Valley

Training Feedback:

<table>
<thead>
<tr>
<th>To what extent would you agree with the following statements</th>
<th>1: Strongly Disagree</th>
<th>2: Disagree</th>
<th>3: Agree</th>
<th>4: Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The content of the training was suitable for my needs</td>
<td>1</td>
<td>2%</td>
<td>2%</td>
<td>24%</td>
</tr>
<tr>
<td>The training was delivered well</td>
<td>1</td>
<td>2%</td>
<td>4%</td>
<td>17%</td>
</tr>
<tr>
<td>The time allocated to training was sufficient</td>
<td>2</td>
<td>5%</td>
<td>2%</td>
<td>16%</td>
</tr>
<tr>
<td>The training will assist me at work</td>
<td>1</td>
<td>2%</td>
<td>5%</td>
<td>19%</td>
</tr>
<tr>
<td>The training environment was suitable for training</td>
<td>2</td>
<td>5%</td>
<td>5%</td>
<td>17%</td>
</tr>
</tbody>
</table>
There has since been further feedback but unfortunately evaluation forms were not completed. The feedback from MK was very positive, and it was found that once one influential clinician was on board, the positivity quickly spread. This highlights that there is a need for a clinical lead in each trust.

Common themes/discussions after training
- Paperwork availability: Teams wanting to start implementing the programme would like their trust to provide the paperwork as soon as possible. Everyone attending training was given advice on how to progress with the ordering process.
- Interest in the development of an electronic version of the paperwork for those that Trusts that are paperless
- Availability in other languages: It is currently only available in English
- There is a clear need for a transition programme, it gives structure and clear targets
- Need for careful organization within each team to be able to implement it
- The paperwork may need tweaking to meet needs of all specialties
- Needs formalizing: Transition policy
- More time needed in clinic to deliver the programme effectively.

15.3 Additional Information:
Printers for the RSG paperwork
Despite going through procurement within the trust initially, the printing costs for the paperwork are far cheaper with a Hampshire based company, used by the team in Southampton. Please see below. Naturally, if an order is made in bulk, the cost is further reduced.

<table>
<thead>
<tr>
<th>Richard Harwood, Managing Director: <a href="mailto:richard@diguru-uk.com">richard@diguru-uk.com</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diguru</td>
</tr>
<tr>
<td>3-6 Avenger Close, Chandlers Ford Ind Est, Eastleigh, Hampshire, SO53 4DQ</td>
</tr>
<tr>
<td>Tel: +44 (0)2380 240710</td>
</tr>
<tr>
<td>Mob: +44 (0)7767 608776</td>
</tr>
</tbody>
</table>

15.4 Proposed Priorities for Transition Steering Groups
Having worked with the RBFT transition Nurse, who has been working closely with the paediatric team at Reading and listening to clinicians concerns, it is believed the following should be addressed:
- A Trust Transition Policy
- Clarity on whether it is suitable to amend the policy for the admission of 16/17 year olds with a long term condition: Appropriateness of admitting vulnerable young people to an adult ward.
- DNA Policy regarding young people (16-25 year olds)
- Implementation of a best practice transition pathway: This will guide all clinicians on the stages of transition, which also incorporates how to use the ready steady go programme but is not specific to the programme
- Development of a database to identify patients at an age suitable for transition: This may be a tick box on the hospital admin system which includes whether the patient has been started on a programme
- Discussions around how to link in with schools for patients with a long term condition and with learning difficulties
- Use of a health handover document: To aid the referral process back from the hospitals to the GP surgery/community (In development by Polly Schofield)
15.5 Transition Policies in Place Across the Network
There is currently no transition policy in place in Oxford, Milton Keynes or Buckinghamshire but sample policies are available to assist the steering groups once established and available on both the TVSCN website and the Oxford intranet page. There is a trust transition guide in place at Wexham, but at this time, no policy. The sample policies have been provided in order to assist with its development. The OUH Network Transition Nurse had not been informed as to whether there has been any development with this at the time of the report.

15.6 Oxford University Hospitals NHS Foundation Trust - Suggested Additional Work
Specialties known to not have any transition service but invited to attend training:

15.7 Transition of Young People Intranet Page
The OUH Network Transition Nurse set up a transition page to act as a central resource for clinicians within the trust to obtain vital information about transition and the RSG programme. The aim was to provide the RSG documentation, access to all supportive transition documents/guides and also provide a map of the transition service provision across the trust. It is believed to be very effective from a number of perspectives. It provides

- all the RSG documentation to all members of the trust
- Information on how the collaborative project came about
- It provides a number of transition documents to inform best practice: CQC 2014, RCN 2013 etc.
- Provides answers to frequently asked questions on the RSG programme
- A comprehensive signposting resource, including disease specific website addresses
- Contact information and service provision details to allow teams to contact and learn from each other
- The opportunity for clinicians to put their name forward for the transition steering group

The website will need minimal maintenance, which could easily be achieved either by a nominated person asking media and communications to make changes, or that person attending a three hour site management training session which would allow them to make any changes/additions themselves.
http://ouh.oxnet.nhs.uk/Transition/Pages/Default.aspx

15.8 Young Person’s Transition Webpage
The OUH Network Transition Nurse worked with the media and communications team in order for them to set up a page on the trusts website for young people to go to for health/education/social advice. This page will also provide information about transition and the preparation they should expect to receive before transferring to adult services. It would additionally provide information about the RSG programme to allow patients to ask their clinicians about how to get involved if they are not already on it. It is suggested that contact be made with Scott Lambert, patient experience project lead for young people, in order to meet their needs and to also advertise this page using social media. This could be used by clinicians to signpost YP to get help and advice on issues outside their specialty, whilst working through the programme, therefore it would act as a tool for both patients and clinicians. The steering group would need to elect/work with the nurse specialists to maintain this with up-to-date resources, but this could be achieved in collaboration with the media and communications team and require minimal work.
15.9 THE TRANSITION EVENT, DECEMBER 11TH 2015
In collaboration with the TVSCN transition team, The OUH Network Transition Nurse assisted in the planning of the transition event in December. The aim of this event is to try and capture the teams that have been unable to attend or arrange a training session on the RSG programme and also to provide teams implementing a transition service with some practical implementation advice. The OUH Network Transition Nurse made contact with clinicians who have successfully implemented a service to talk about their experiences of transition clinics and the use of the ‘Hello’ questionnaire within the adult service. She also liaised with the Southampton team in order to get their support with the event.

15.10 RECOMMENDATIONS
- All trusts set up a transition page on their intranet sites, to ensure that support is provided to all teams looking to improve their service, provide easy to access RSG resources and also map the current transition service provision.
- Oxford to progress with setting up the young persons’ webpage and feedback whether this is a useful resource for young people and clinicians, to consider implementation across the Network.