Ready Steady Go and ‘Hello’
delivering
Patient empowerment
Shared decision making
Transition

Implementing transition for young people with complex medical needs and their families
Transition

• “a purposeful, planned process for adolescents with chronic physical & medical conditions as they move from child-centred to adult orientated health care.
  
  *Blum et al 1993*

• A **process** that addresses their
  — Medical needs
  — Psychosocial needs
  — Educational/vocational needs

  **Patient empowerment**

Empower the patient!

*Equip the Young person with the knowledge and skills and confidence to manage their condition in children’s and adult services*

• Introduce the YP to adult services
• Ready the adult services for the Young person
Transition

“a purposeful, planned process for adolescents with chronic physical & medical conditions as they move from child-centred to adult orientated health care.

Blum et al 1993

**A process** that addresses their
– Medical needs
– Psychosocial needs
– Educational/vocational needs

*Transfer is a single event*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Diagnosis/Study</th>
<th>Attendance Paediatrics: %</th>
<th>Adults: % @ 2yrs post transfer</th>
<th>70-80% reach adult life</th>
<th>Mean death 25.4yrs</th>
<th>1:5 premature/avoidable</th>
<th>13/95 patients died – shunt failure</th>
<th>Renal transplants 3 yrs post transfer</th>
<th>8/20 failed - 7 were unexpected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>Kipps et al 2002</td>
<td>94%</td>
<td>57% @ 2yrs post transfer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Renal transplants 3 yrs post transfer</td>
<td>8/20 failed - 7 were unexpected</td>
</tr>
<tr>
<td>Congenital heart disease</td>
<td>Sommerville 1997</td>
<td>70-80% reach adult life</td>
<td>Mean death 25.4yrs</td>
<td>1:5 premature/avoidable</td>
<td></td>
<td></td>
<td></td>
<td>Renal transplants 3 yrs post transfer</td>
<td>8/20 failed - 7 were unexpected</td>
</tr>
</tbody>
</table>
| Hydrocephalus                    | Tomlinson et al 1995| Attendance Paediatrics: 100% | Adults: 40% @ 2yrs post transfer | 13/95 patients died – shunt failure | Renal transplants 3 yrs post transfer | 8/20 failed - 7 were unexpected | DOH 2006

**Why is transition needed?**
How many young people with a kidney transplant had a poor outcome (loss/death) within 2 years of transfer to adult services with?

- **NO TRANSITION**: 25%
- **TRANSITION**: 0%

Prestidge et al. 2012
Ready Steady Go delivers on:

- Best practice statement for transition – Renal, Cancer, Diabetes, Mental Health...
- CQC report: From pond into the sea (2014)
- Health Foundation: Ideas into action: Patient centred care (2014)
- NHS England generic transition service specification

Patients in control: Why people with long term conditions must be empowered. *IPPR 2014*

- Named contact
- Better information and advice
- Healthcare plans
- Ownership of medical records
- Peer support
- Personal health budgets
Patient empowerment: for better quality, more sustainable health services globally

- Patient empowerment
- Central resources
- Change Healthcare professional behaviour
- Electronic owned-patient records

Longitudinal study of the transition of young people with complex health needs from child to adult health services

- Promotion of young person to manage their condition
- Meet adult team pre-transfer
- Appropriate parental involvement

Colver et al 5 yr NIHR funded study 2017
**Ready Steady Go: What?**

A holistic transition programme to empower patients and carers by:

- Equipping them with the skills and knowledge to manage their condition
- A gradual process NOT a single event

[www.uhs.nhs.uk/readysteadygo](http://www.uhs.nhs.uk/readysteadygo)

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**Ready Steady Go: How?**

Provides a structured framework covering:

- Knowledge
- Self advocacy - speaking up for yourself
- Health + lifestyle
- Education/future
- Psychosocial issues
- Transition

Paone et al 1998, J McDonagh et al 2006
Ready Steady Go: Self advocacy

- Speaking up for yourself
- Shared decision making

‘No decision about me without me’

Ready Steady Go: How?

Provides a structured framework covering:

- Knowledge
- Self advocacy - speaking up for yourself
- Health + lifestyle
- Education/future
- Psychosocial issues
- Transition

Paone et al 1998, J McDonagh et al 2006
Ready Steady Go: Who?

- You, if you are 11+ years old with a long-term condition
- You, if your child is 11+ years old
  - Parent/carer plan
- Start early because
  - More time to gain the knowledge, skills and confidence
  - Better knowledge retention
  - Not rushed- go at the patient/carer pace!
**Ready Steady Go: Moving through the programme**

**Ready Steady Go: Each Young person (YP) progresses at their own pace**

- **11-12 yrs**
  - YP and carer introduced to Ready Steady Go programme with information leaflet + video
  - www.uhs.nhs.uk/readysteadygo

- **11 – 13 yrs**
  - YP completes Ready Steady Go programme with information leaflet + video
  - Issues addressed in bite sized pieces
  - YP introduced to Ask 3 Questions + confidentiality
  - When ready YP seen on own for few mins during clinic

- **14 – 16 yrs**
  - YP completes Steady issues addressed in bite sized pieces
  - Aim to see YP for longer on own in clinic
  - Keep parent/carer fully involved
  - Clinic letters written to YP

- **16 – 18 yrs**
  - YP completes Go issues addressed in bite sized pieces
  - Work towards YP conducting whole clinic on own
  - Keep parents/carers involved
  - Referral letter to adult team

**1st adult clinic**

- YP +/- carer completes Hello issues addressed in bite size pieces
- YP meets adult team
- Time issues highlighted to adult team
- Ideally all issues addressed prior to transfer

**Carer completes parent/carer questionnaire alongside YP questionnaires. Any issues addressed.**

**YP with learning difficulties completes as much as possible alongside carer who is YP advocate.**

**Ready Steady Go: Snapshot Feedback**

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>The “Transition: moving into adult care” helped patients + family understand why they are starting RSG</td>
<td>104/104 agree</td>
</tr>
<tr>
<td>The questionnaires were easy to understand</td>
<td>104/104 strongly agree/agree</td>
</tr>
<tr>
<td>RSG questionnaires helped focus clinic appt + address difficult issues</td>
<td>101/104 agree</td>
</tr>
<tr>
<td>RSG helps ease the process of transition</td>
<td>104/104 strongly agree/agree</td>
</tr>
<tr>
<td>RSG improved my practice</td>
<td>25/26</td>
</tr>
<tr>
<td>Any questions that would help improve transition?</td>
<td>All – No</td>
</tr>
</tbody>
</table>
| Comments? | Time issues
Relevance of some questions especially in patients with learning disabilities |
Ready Steady Go: Outcomes

<table>
<thead>
<tr>
<th>Outcomes for young people within 2 years of transfer to adult services (Diabetes)</th>
<th>No transition</th>
<th>Transition with Ready Steady Go</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of YP attending clinic in adult services</td>
<td>57%</td>
<td>78%</td>
<td>only had time to complete ‘Go’ as patients older</td>
</tr>
<tr>
<td>Diabetes related emergency hospital admissions</td>
<td>1.01</td>
<td>0.45</td>
<td>50% reduction only had time to complete ‘Go’ as patients older</td>
</tr>
</tbody>
</table>

L. Cable, N Davis 2015

Ready Steady Go: Making it happen

- Ready Steady Go (RSG) documentation
- Information campaign
- Cohorting clinics (11+ weeks 4/year)
  - Promotes transition
    - MDT, patients and parents
  - Share resources
  - Young person friendly environment
Ready Steady Go + Hello: Uptake

- Adopted across the UK
- Across sub-specialties

- **RSG** and **Hello:** is used in 96% UK renal units using a transition tool. *Hamilton et al 2017*

- NICE published **RSG** as a shared example of good practice

Ready Steady Go + Hello: Uptake

- **RSG** voted best transition out of 11 international tools. ‘Summer School Children & Adolescents with Chronic Conditions’ Lausanne (2016)

- **RSG:** Translated into French, Spain, Dutch, Portuguese........
**Ready Steady Go:**

- My Medical Record- patient owned e-record
  - Includes online/app **Ready Steady Go**

- Implementing ‘Hello’ in adult services
- ‘Hello’ to children’s services for parents/carers
- Easy read **Ready Steady Go** and ‘Hello’

- Central resources of information
  - [www.infokid.org.uk](http://www.infokid.org.uk) (BAPN+RCPCH+ BKPA)

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**Ready Steady Go + Hello: Summary**

- A generic programme that works across sub-specialities and age groups
- Shifts emphasis to **empowering** the young person and adult patient

**RSG succeeds because:**

- The staged ‘traffic light system’ is appealing, it’s simple to use, easy to implement and has minimal cost- **sustainable**

- **RSG-Hello** continuity from paediatrics to adults
Patient empowerment: for better quality, more sustainable health services globally

- Patient empowerment
- Central resources
- Change Healthcare professional behaviour
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*All Party Parliamentary Group on Global Health 2014*
The Ready Steady Go transition programme - Getting Ready

**KNOWLEDGE**

- I can describe my condition
  - Yes
  - I would like some extra advice/help with this

**Comments:**

```
I was a baby when I was diagnosed. Please can you tell me more
```

- I know when to take my medications, names, doses, how often etc.
  - Yes

---

Easy Read **Ready Steady Go**

**Knowledge**

- I know about my medicines and treatments
  - Yes
  - I would like some help

**Comment:**

```
Go Back
Next
```

- 4%
Some practical uses... Key demographics

Some practical uses... Appointments and record management
Some practical uses... Electronic document delivery

Documents

We will display links to your patient documents held by us, as they become available. You may receive documents that you would normally get through the post but this is not a replacement for that service.

My documents

<table>
<thead>
<tr>
<th>Date Downloaded</th>
<th>Name</th>
<th>Size</th>
<th>Expired</th>
<th>Notes</th>
<th>Active</th>
</tr>
</thead>
<tbody>
<tr>
<td>05/09/2013 11:25am</td>
<td>V92 Assessment.pdf</td>
<td>3MB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>05/09/2013 11:25am</td>
<td>Respiratory Medicine review.pdf</td>
<td>14KB</td>
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<tr>
<td>05/09/2013 11:25am</td>
<td>General Notes.pdf</td>
<td>20KB</td>
<td></td>
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<tr>
<td>05/09/2013 11:25am</td>
<td>Discharge summary.pdf</td>
<td>66KB</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Some practical uses... Medications

Medications

Please use this page to track and manage your medications. We may update this list where we hold relevant data.

My medications

<table>
<thead>
<tr>
<th>Date Started</th>
<th>Medication Items</th>
<th>Strength</th>
<th>Dosage</th>
<th>Date Discontinued</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>01/02/2013</td>
<td>Temazepam</td>
<td>2 Millitres/4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Some practical uses... Online journals

Food diary

How to use the food diary
1. Make a note of all food and drink consumed including quantities, for example soups, sauces, or slices, in the week leading up to your appointment with the dietician. Write down everything you eat and drink, including water.
2. Please do not skip your normal diet just because you are completing this diary.
3. State the brand name of manufactured foods.
4. If any dishes are home baked, for example cakes or puddings, please make a note of the recipe in the food diary notes column.
5. Please note any symptoms you experience for example stomach pain or diarrhoea, in the food diary notes column along with the time the symptom was experienced.

My food diary

<table>
<thead>
<tr>
<th>Date</th>
<th>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6/1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7/1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8/1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9/1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10/1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11/1</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Some practical uses... Secure messaging

Compose New Message

Message Inbox

<table>
<thead>
<tr>
<th>Date</th>
<th>Received From</th>
</tr>
</thead>
<tbody>
<tr>
<td>01/04/2015</td>
<td>Seen Patient</td>
</tr>
<tr>
<td>02/02/2015</td>
<td>Seen Patient</td>
</tr>
<tr>
<td>03/03/2015</td>
<td>Seen Patient</td>
</tr>
<tr>
<td>04/03/2015</td>
<td>Seen Patient</td>
</tr>
<tr>
<td>05/03/2015</td>
<td>Seen Patient</td>
</tr>
<tr>
<td>06/03/2015</td>
<td>Seen Patient</td>
</tr>
</tbody>
</table>
Clinically relevant conversation

Date: 02/03/2017 07:11:42 From: 
Subject: RE: Fluid chart
Is that a good amount of urine or too much? I will phone the ward I am working today but will plan to fit him in.
Thank you

Date: 01/03/2017 23:45:12 From: Ready Steady Go Team - Arvind Nagra
Subject: RE: Fluid chart
Hi,
Thank you for the completed fluid chart. It shows he passes approximately 950 ml of urine a day and drinks approx. 1200 ml.

Easy Read Ready Steady Go

Knowledge
Easy Read Home Instructions Check My Answers

I know about my medicines and treatments

Comment:

Go Back 4%

Next

University Hospital Southampton
MyMR: Next steps

- Easy Read **Ready Steady Go** and **Hello**
- Emergency management plan tab
- Learning disabilities
  - Agreed admission plans in place
  - ‘All about me’ tab
- Centile Growth charts + Vaccinations
- ...

Delivering **better quality** and **sustainable** health services

www.uhs.nhs.uk/readysteadygo
Ready Steady Go and Hello

Free Information/resources can be found at:
• www.uhs.nhs.uk/readysteadygo

• Implementing transition: Ready Steady Go.
Arch Dis Child Educ Pract Ed June 2015
http://ep.bmj.com/content/100/6/313

Arvind.nagra@uhs.nhs.uk

TOGETHER WE CAN MAKE A DIFFERENCE!