South Thames Paediatric Network
Transforming Healthcare for Children and Young People

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NHS Alder Hey Children's NHS Foundation Trust

NHS University Hospitals Birmingham NHS Foundation Trust

NHS Imperial College Healthcare NHS Trust

NHS Somerset NHS Foundation Trust

Burdett National Transition Nursing Network and the South Thames Paediatric Network Collaboration Events

Stella Carney

Burdett Regional Nurse Advisor for Young People's Healthcare Transition (South of England)

Louise Porter

National Lead Nurse – Burdett National Transition Nursing Network

Final Session

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The Burdett National Transition Nursing Network - Meet Our Team

Funded by the Burdett Trust for Nursing, this national team of expert nurses are leading the implementation of the Quality Improvement (QI) Model for Transition Improvement across the four regions of England

Over the three years our team of Regional Nurse Advisors (RNAs) will outreach to:

- Lead the implementation of the QI Model for Transition Improvement
- Identify and support organisation transition champions/leads to work through the QI process with their services/teams to improve or develop new transition pathways
- Provide opportunities to learn from and collaborate with other trusts
- Develop a national network to create a culture of system wide learning and sharing
- Work with an experienced team of researchers in transition to evaluate the use of the Transition QI model

The team have a wide range of expertise and look forward to supporting you in improving the transition experience for young people and their families

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Louise Porter

National Lead Nurse
Leeds Teaching Hospitals NHS Trust

Louise is a Paediatric Nurse who has held multiple leadership roles and holds a business management degree. Louise led the original project in Leeds; developing and implementing the QI Model for Transition Improvement and leads this national team

louise-c.porter@nhs.net

Emma Powell

RNA North
Alder Hey Children's NHS Foundation Trust

Emma is a dual qualified Paediatric and Public Health Nurse and qualified clinical educator. Emma has specialist knowledge of SEND and has held senior strategic positions within both Health and Local Authority settings

emma.powell@alderhey.nhs.uk

Nathan Samuels

RNA Midlands & East
University Hospitals Birmingham NHS Foundation Trust

Nathan is a dual qualified Learning Disabilities and Public Health Nurse with extensive experience in mental health, public health and learning disabilities in both acute and community settings across the West Midlands

nathan.samuels@uhb.nhs.uk

Nigel Mills

RNA London
Imperial College Healthcare NHS Trust

Nigel is a senior Paediatric Nurse who has worked with young people in settings including dedicated general adolescent and oncology units and in recent years as Transition Lead at a Tertiary Children's hospital

nigelmills@nhs.net

Stella Carney

RNA South
Somerset NHS Foundation Trust

Stella is a Senior Paediatric Nurse with extensive leadership and management experience. Stella has worked in a variety of Acute Hospital settings, including managing a number of departments. Prior to her nursing career, Stella spent 17 years working within the pharmaceutical industry,

Stella.Carney@SomersetFT.nhs.uk

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Aim for Transition

Aim

- To improve the experience of young people age 11 to 25 years with a Long Term Condition (LTC) whilst also improving the experience of their families / carers, during the process of moving from children's services to being cared for and settled in adult services.
- In doing so having a positive impact on long term health outcomes, achievement of life aspirations and attainment of life goals.

Objectives for Transition Collaborative Events

Objectives

- To provide organisations with access to expert knowledge of Transition.
- Introduce an evidence based Nationally recognised QI process, to guide and support organisations in developing effective and sustainable Transition Services.
- To support the development of a Network of Transition contacts within organisations across the South Thames region as part of the wider Regional and National Transition Nursing Network.

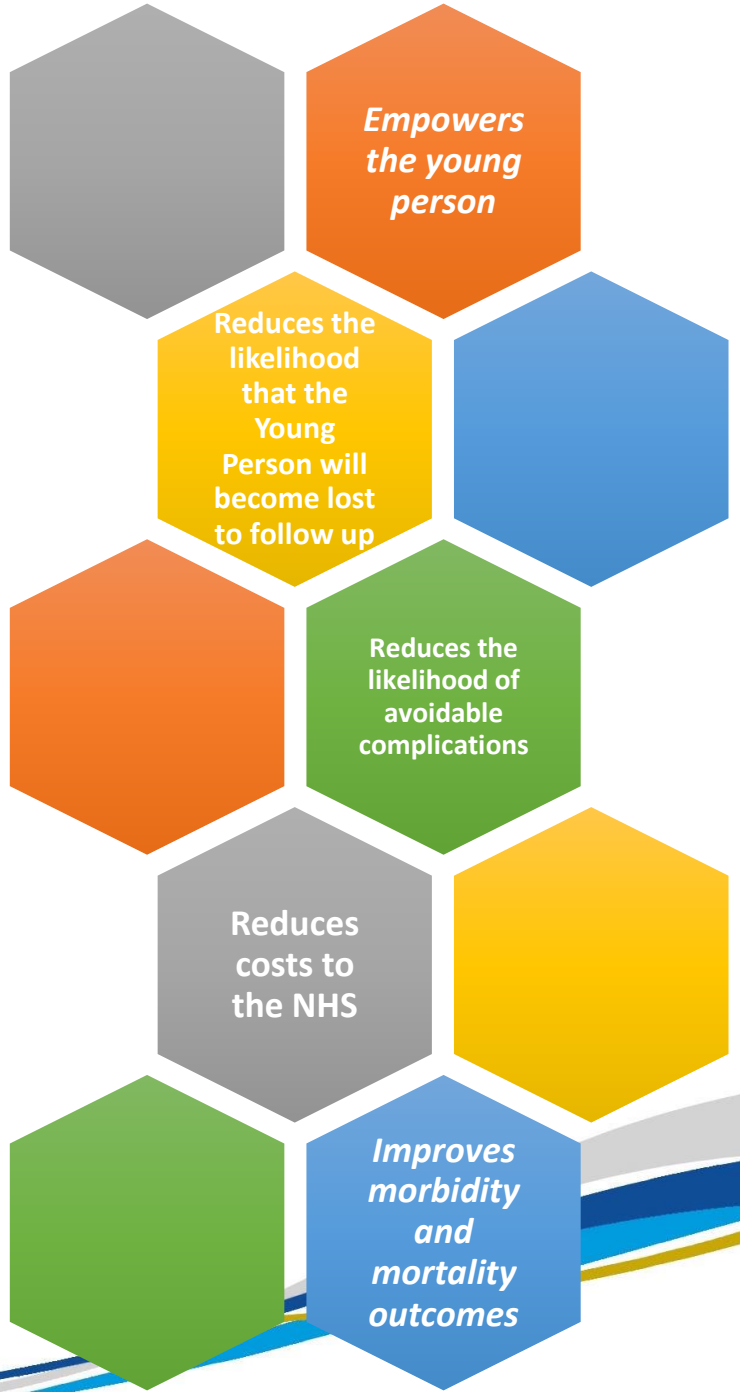
Transition – What it is and what it is not

- Blum et al (1993), stated that the aim is for Transition to be a planned, purposeful movement of a Young Person from a child centred to an adult orientated health care system.

- It is a process that evolves over a considerable amount of time and should NOT be considered a single event.

Transition

Effects & Benefits



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Effects of Poor Transition

The lack of co-ordinated care between child and adult services:

- Creates anxiety and unnecessary distress for young people, their families and carers
- Often results in poor compliance with treatments
- Frequent visits to hospital
- Poor engagement with Healthcare Services
- Poor social engagement and mental health

This contributes to increasing healthcare costs, but more importantly leads to poor health outcomes including poor mortality and morbidity.

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Burdett National Transition Nursing Network and the South Thames Paediatric Network Collaboration Events

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Session 1: 29/11/2022

This session is to launch the collaboration events. Each session would include a call to action for attendees to tangibly begin work on developing their Transition services.

It will include:

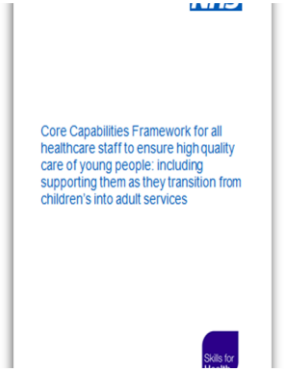
- An introduction to the Burdett National Transition Nursing Network.
- National & Regional Transition Updates.
- Transition best practice principles.
- Introduction to the Burdett Transition QI project.
- Breakdown of future programme sessions planned.
- The Burdett Transition Support offer.
- 1:1 Burdett Coaching to deliver QI principles.

Call to action for individuals to complete the following pieces of work in preparation for the next session.

- Identifying your individual organisations visions, aims and objectives for Transition.
- What does your service look like now - Data collection and mapping your service.

Session 2: January 2023

- An overview of the key National Guidance and Frameworks informing the development of Transition Services - Understanding Transition and building an effective and sustainable Transition Service.
- An overview of the Transition Project Plan, including how to get started.
- Listening to and understanding Young People's development needs – using HEEADSSS, to support and guide conversations with young people.



Key Documents

Project Plan

How to get Started

Session 3: February 2023

- National Update
- Stakeholder Analysis
- Transition Tools – Ready, Steady Go and Growing Up and Gaining Independence (GUGI)

Session 4 : April 2023

Implementation

- Training needs analysis
- Communication strategy
- Delivery group roles and Responsibilities
- Patient Pathways roll out

Transition Leadership

- The role of a Transition Lead

International Learning

- International Transition Toolkits

Implementation

Transition Leadership

International Transition Toolkits

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Transition National Key Documents and Guidelines

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What do we mean by best practice ?

Services have a live patient register in place. This is a list of all patients in transition - core elements Inc. name, age, use of RSG, planned date of transfer & destination

Patient Experience & Engagement data is available – evidence to indicate that patients are; getting the right info at the right time, attending appointments & actively engaging in healthcare (FFT, case studies, films, interviews, questionnaires/surveys, transition events/evenings)

Services meet any transition elements of NHSE Specialist Service Specifications (if relevant)

Meeting NICE Guidance & standards

Service specific long term health outcome measures are in place and monitored e.g. Hba1c, graft retention, lung function test results

Services are actively monitoring and reviewing patients over the age of transfer in children's services (6 monthly transition plan review, risk assessment & escalation via MDT governance process if required)

All eligible patients have transition plans in place

Services have been benchmarked against You're Welcome Quality Criteria

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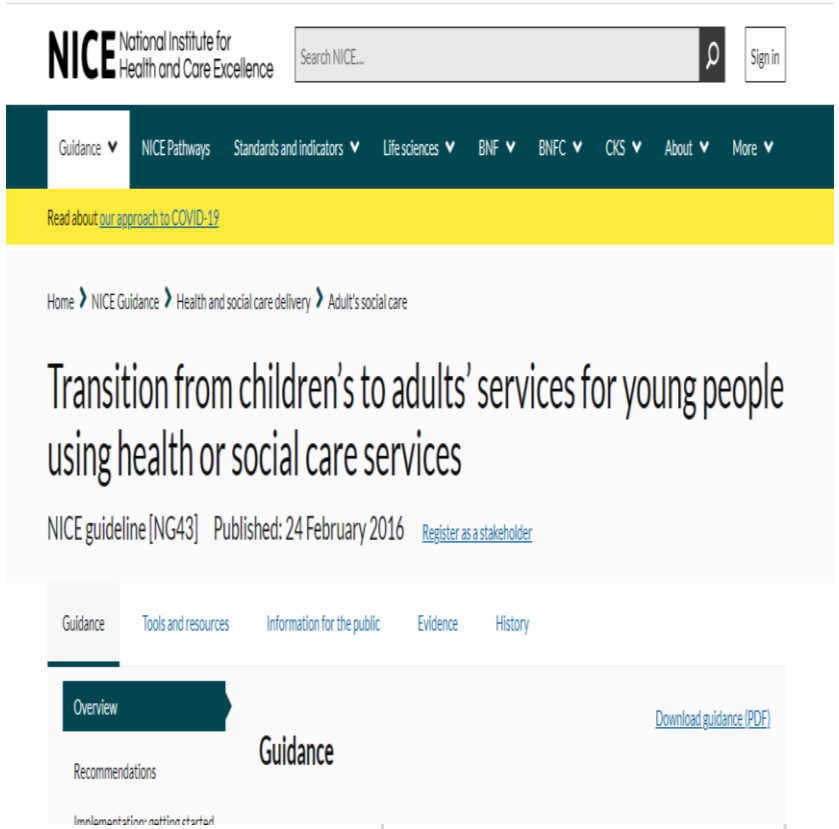
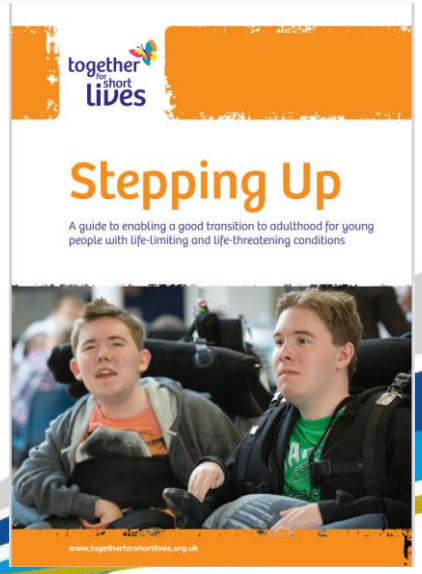
Current Guidance

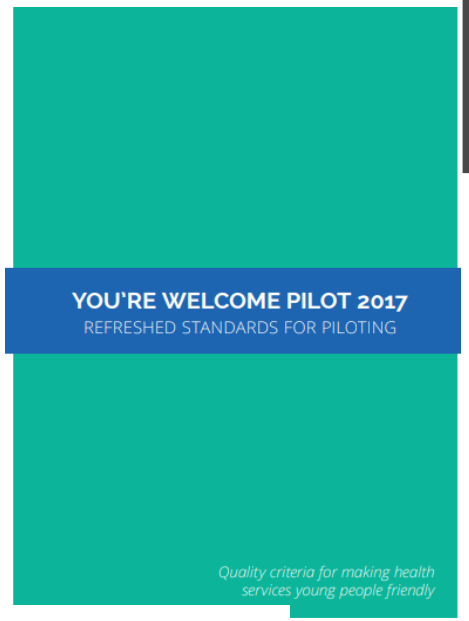
- NICE Guidance 2016
- NICE Standard 2016
- You're welcome 2017
- SEND code of practice
- TFSL Guide to stepping up 2016
- Northumbria tool kit for transition 2018

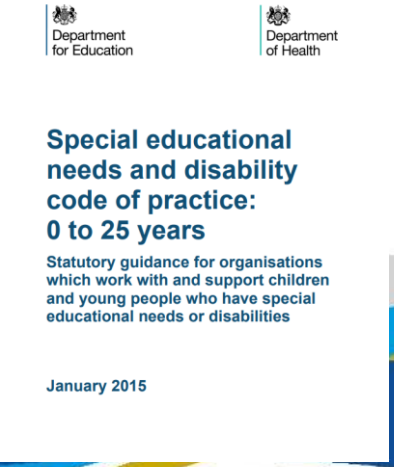
Transition Tools

- HEEADDESSS
- RSG
- GUGI
- 10 steps









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NICE Transition Guidelines NG43 (2016)

- 'covers the period before, during and after a young person moves from children's to adults' services.'
- 'help young people and their carers have a better experience of transition by improving the way it's planned and carried out. '
- 'covers both health and social care.'

56 recommendations

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NICE Quality Standards

1) Young people who will move from children's to adults' services **start planning their transition** with health and social care practitioners by school year 9 (**aged 13 to 14 years**), or immediately if they enter children's services after school year 9.

2) Young people who will move from children's to adults' services have an **annual meeting to review transition planning.**

3) Young people who are moving from children's to adults' services have a **named worker to coordinate care and support before, during and after transfer.**

4) Young people who will move from children's to adults' services **meet a practitioner from each adults' service** they will move to before they transfer.

5) Young people who have moved from children's to adults' services but **do not attend their first meeting** or appointment are contacted by adults' services and **given further opportunities to engage.**

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NICE Transition Guidelines NG43 (2016) – Overarching Principles

It is estimated that up to 15% of young people aged 11 – 15 have a long term condition that requires ongoing specialist care

Transition into adult services can take up to seven years to complete

- Managers in **Children's and Adult services need to work together** to enable a smooth Transition
- Examples of good practice include having a **joint mission statement and information sharing protocols**
- Transition plans need to **reflect the individuals capabilities and preferences,** and young people should be asked regularly about parent or carer involvement
- Before Transfer, they should be able to **meet with someone from adult services** and **choose a named worker** to help them navigate the Transition Process.

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You're Welcome Pilot 2017 (Update commissioned)

- **The Department for Health's Quality Criteria for Young People friendly health services**

Includes:

Accessibility

Publicity

Confidentiality and consent

Environment

Staff training, skills attitudes and values

Joined up working

Young people's involvement in monitoring and evaluation of patient experience

Health issues for young people

Sexual and reproductive health

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Northumbria Developmentally Appropriate Healthcare

- **The toolkit is designed to support all working in the NHS, from clinicians to chief executives, to promote the health of young people and to play their part in making healthcare work for this age group.**

Supports:

- Understanding biopsychosocial development and holistic care
- The acknowledgement of young people as a distinct group
- Adjustment of care as the young person develops
- Empowerment of the young person by embedding health education and health promotion in consultations n Working across teams and organisations.

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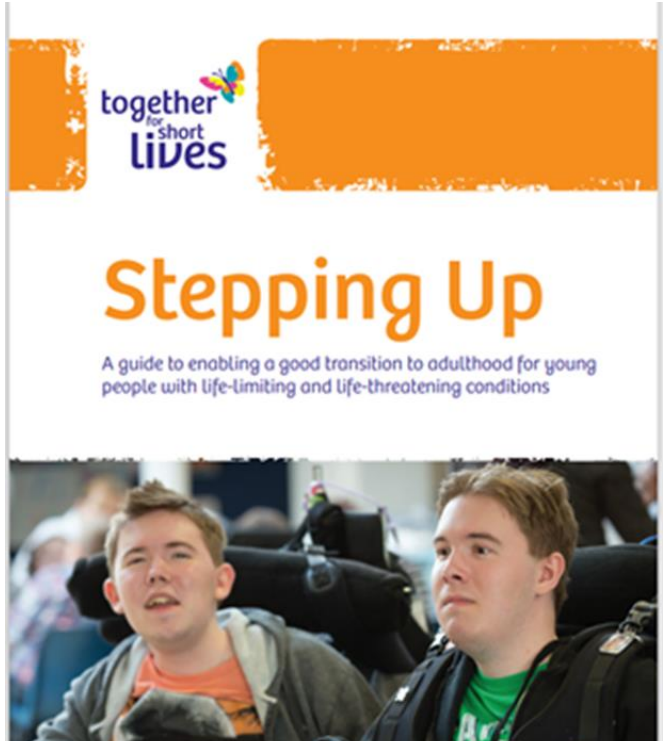
Together for Short Lives - Stepping Up



- A guide to enabling a good transition to adulthood for young people with a life-limiting and life-threatening conditions

- *Currently being updated*

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SEND Guidelines

- Provides statutory guidance on duties, policies and procedures relating to Part 3 of the Children and Families Act 2014 and associated regulations and applies to England.
- It relates to children and young people with special educational needs (SEN) and disabled children and young people.
- A ‘young person’ in this context is a person over compulsory school age and under 25.

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The Burdett National Transition Nursing Network

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Burdett Transition Quality Improvement Model

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Where to start ….

- What is the look of transition?
- How many services do we have that have transition patients (will need to continue care in an adult service)?
- What is the risk?
- How do we identify and monitor patients in transition?
- What guidance do we need to follow?
- What do we have to report on?
- What do we want to report on?

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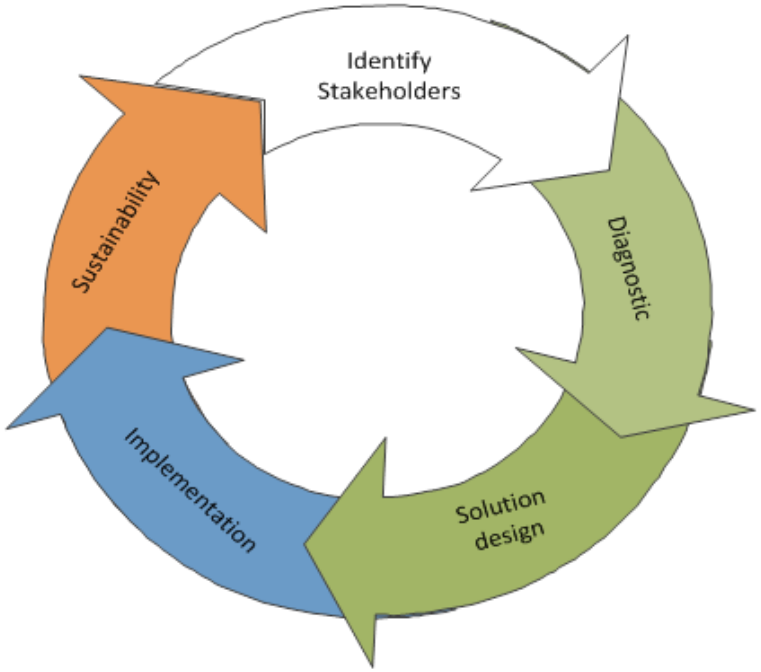
Project Plan for Services

Service project plan	Identify key stakeholders	Identify key stakeholders for transition in the service
		Create delivery group for the transition project work-stream (e.g. service Renal, Diabetes, Allergy etc.)
		Create Stakeholder list and perform stakeholder analysis (use stakeholder analysis grid)
		Create focus groups to assist the delivery group (if required e.g. patient / youth forum for feedback)
	Understand current state	Understand the current transition process and who is involved (use mapping sheet)
		Understand current documentation used
		Identify where patients are currently seen by medical / nursing staff when in transition
		Identify where patients are currently seen by other professionals when in transition
		Understand what information patients are currently given when in transition
		Identify concerns and potential risks and issues in the transition pathway
	Gather good practice from elsewhere	Look at other service specific centres in the UK
		Look at other specialities within your organisation providing good practice for transition
		Look at other specialities outside of your organisation providing good practice for transition
	Define future state (Including You're welcome criteria)	Benchmark service against best practice using the University of Surrey's benchmarking tool
		Define best practice for your service including the use of the 'you're Welcome Criteria'
		Use a transition programme documentation tool, e.g. Ready Steady Go, GUGI, Alder Hey 10 Steps etc.
		Develop best practice future state patient pathway for transition
		Identify gaps between current state of transition pathway and future desired state pathway
		Identify and agree new roles and responsibilities
	Training needs analysis and gap analysis	Identify skills / knowledge required to deliver the future state transition programme to patients and families
		Identify gaps between current skills and desired skills and knowledge
		Identify staff groups / individuals to be trained and level /package of training required
	Communicate	Feedback the defined current state transition pathway
		Feedback any good practice gathered from elsewhere
		Communicate future state
		Communicate new roles and responsibilities
		Communicate work within the project to wider stakeholders
	Train and educate align new R&R's	Create training programme
		Identify trainers / methods of training: face to face, e-learning, practical, shadowing etc.
		Implement training programme (clear aims, objectives, methods of assessment & timescales)
		Ensure time allocated for training
	Implement	Roll out use of the new transition patient pathway
		Delivery group to support staff in use of the new transition pathway
		Consider formal start / launch date for new roles & responsibilities for better impact
		Agree how, when and who will collect measurement data and set a date to review of findings and pathway

The process for improvement



- Stakeholders
- Diagnostic
- Solution design
- Implementation
- sustainability

A structured way of approaching improvement

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Stakeholders

Identify key stakeholders	• Identify key stakeholders for transition in the service • Create delivery group for the project work-stream • Perform stakeholder analysis • Create focus groups to assist the delivery group	➢ Anyone who has interest in or influence over transition ➢ Look at every aspect of transition eg. Heads of Nursing, Chief Exec, parents, adult services, LD Lead also LA colleagues, primary care, commissioners etc. Think about representation at all levels eg. HCAs, admin, MDT coordinator etc. People who are going to deliver are part of the design process. ➢ Delivery Group is term we use but could be focus group, steering group, project group etc. Need representatives from who is delivering transition eg. Both adult and children's services, therapies etc. ➢ Look at contacting the transformation teams, consider QI training. Involve from beginning. Also comms team (will be more involved later on but think about involving from the start). Patient Experience team (may manage volunteers/YP forum etc.) and Audit team too. ➢ Create a stakeholder list, put together as examples above. Look at Power and Influence of stakeholders. ➢ Identify who might be barriers and will be levers. Put into categories and work out communication plan ➢ Consider meeting face to face if possible with flip charts and post-it notes. NB. Take photo to type up before moving!

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Stakeholder Analysis Grid

Enablers:

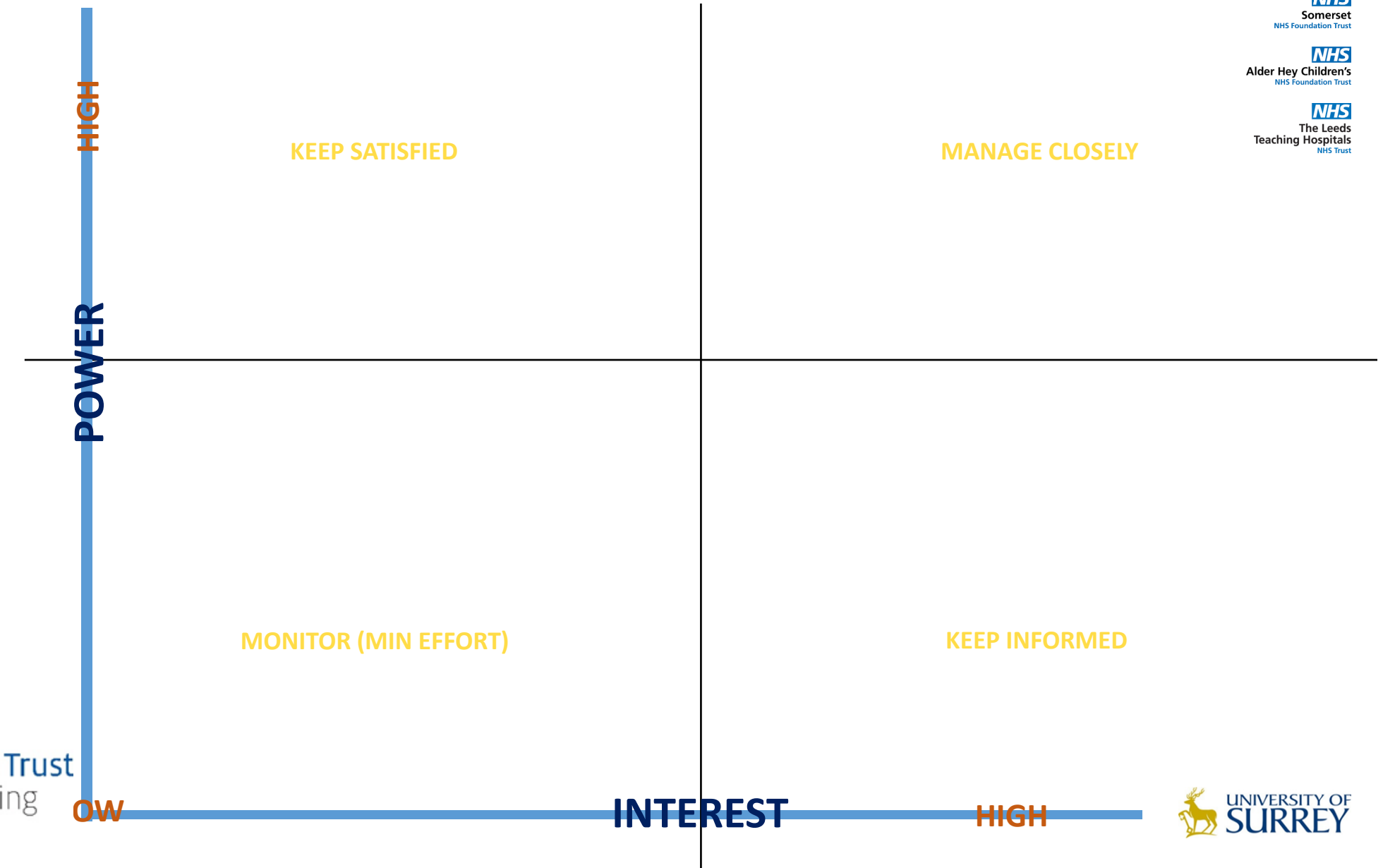
- Think about who has the power and influence. Who are the enablers?
- Identifying these stakeholders early, will allow you to build relationships and bring them with you in the process, rather than having to ‘sell’ them concepts in the future.

Gatekeepers:

- What and who might be barriers to progressing your service.
- This group are equally as important to involve in your policy and process development from the start.

Healthcare Transition

Stakeholder Analysis Grid



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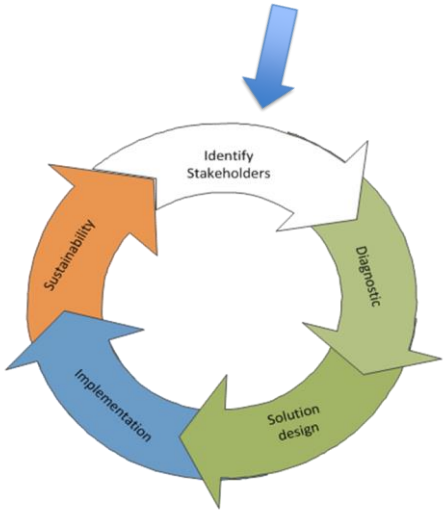
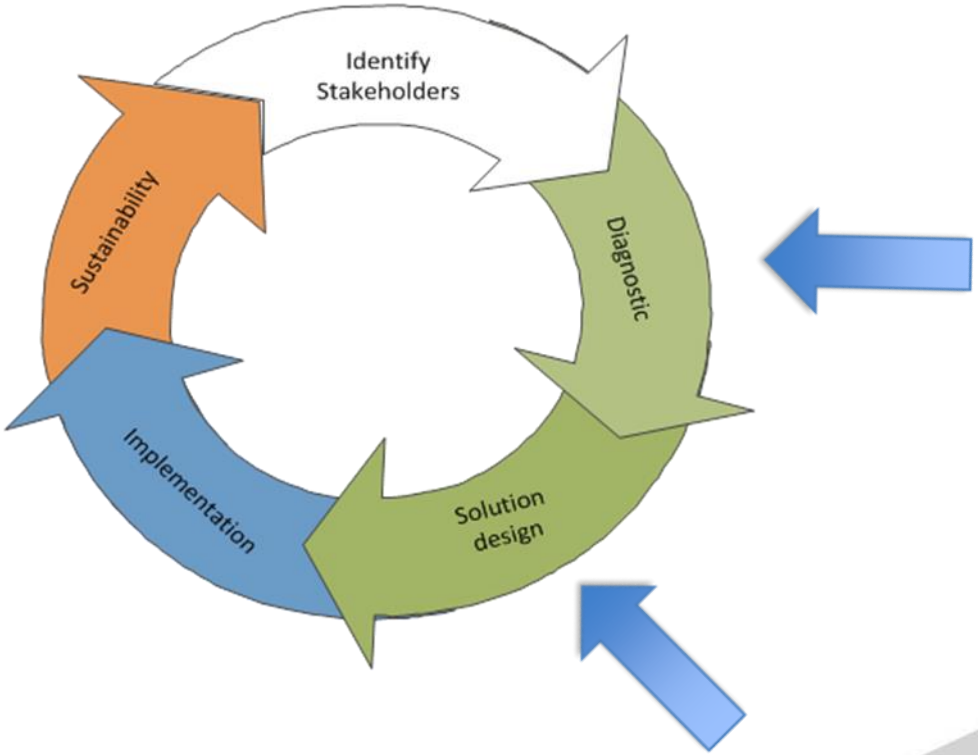
Stakeholder Analysis – Key Points



- Consider internal and external Stakeholders.
- Adult and Children's services should be represented.
- Identify who are the influencers and who are potential barriers to progress.
- Complete a Stakeholder analysis grid to develop a communication plan.
- Create a Focus group to develop and agree the overarching Transition Strategy and include documented action plans (Highlight roles, responsibilities and timelines)
- Focus group to work collaboratively with the service specific delivery group to ensure consistency and develop bespoke Transition Pathways for each service.

Diagnostic and solution design



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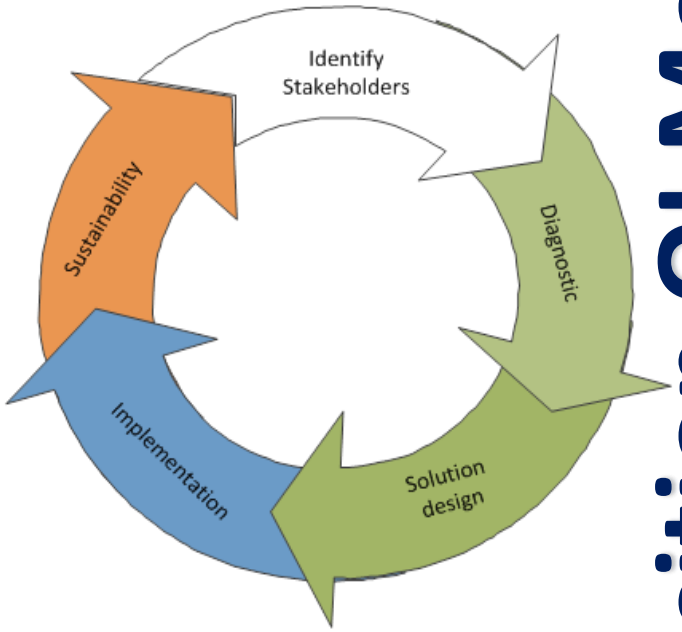
Mapping Your Service

Transition QI Model



Current State
What does the Service look like now?

Mapping Your Service

Future State
What should the Service look like in the future?

Mapping Process

Identifying Stakeholders

Diagnostics

Solution Design

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Understanding the current State of Transition Services

What does your Transition Service look like currently?	Who is involved in developing and delivering the service?	Where are patients currently seen, who by and how often?
Which other professionals will need to be involved and where will they be accommodated?	What policies and processes are in place ?	What documentation is to be used including a Transition Toolkit
Is the environment suitable for YP (You're Welcome Criteria)	Are there any risks, concerns or potential issues?	What is the follow up process?

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Gathering Good Practice

- Look at other specialities **within your organisation** providing good practice for transition
- Look at other specialities **outside of your organisation** providing good practice for transition
- Look at other **service specific specialists centres** in the UK
- Consider **international experience** too; medical colleagues may have worldwide contacts.
- **Consider buddying up of services and organisations** and looking across stakeholders offering different services.
- Have **you looked at all outstanding practice**, not just within your own region but on a national front?

Why Benchmark?

The following comments were made by groups piloting the benchmarks for transition about their potential usefulness:

- The benchmarks provide a focus for discussion between child and adult teams.
- Allows teams to look at where they have been, where they are now and where they want to go as a service.
- Having the benchmarks allows the team to look at transition more formally.
- There were things that team members thought happened in their service but now realise they do not happen.
- There were elements of transition that teams thought they were doing well but after discussion realised they could improve.
- Services that are in their infancy can learn from what others are doing – the benchmarks facilitate these discussions and sharing.
- Good to have a document to show team members and engage them in thinking about transition.

Benchmarking Services

London South Bank University

orchid
Centre For Outcomes And Experience Research In Children's Health, Illness And Disability

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

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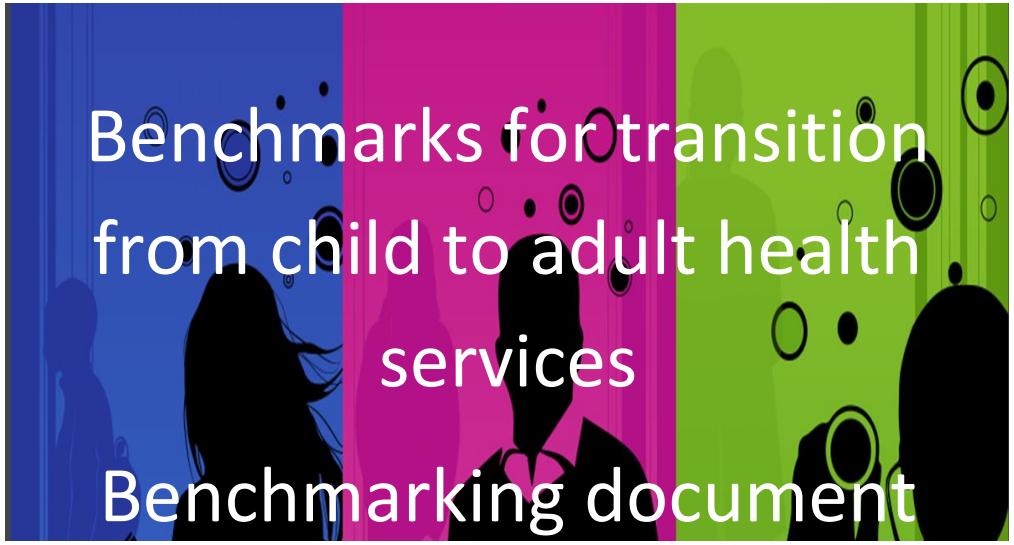

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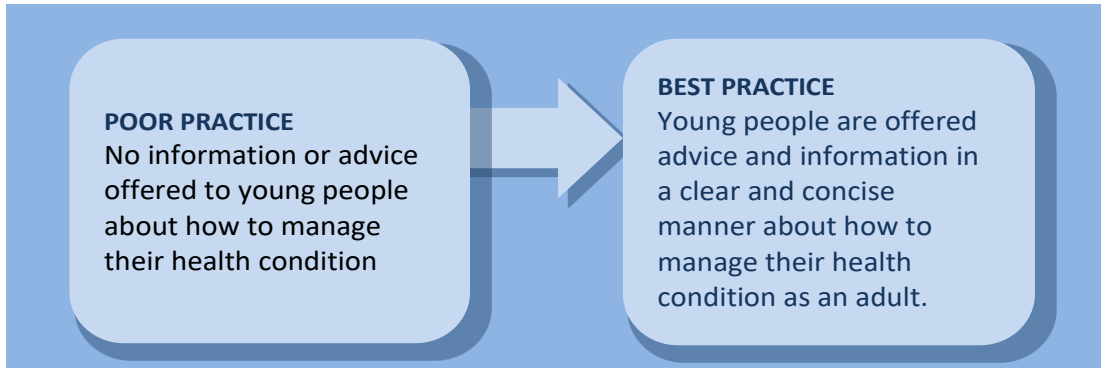
Benchmarking Services

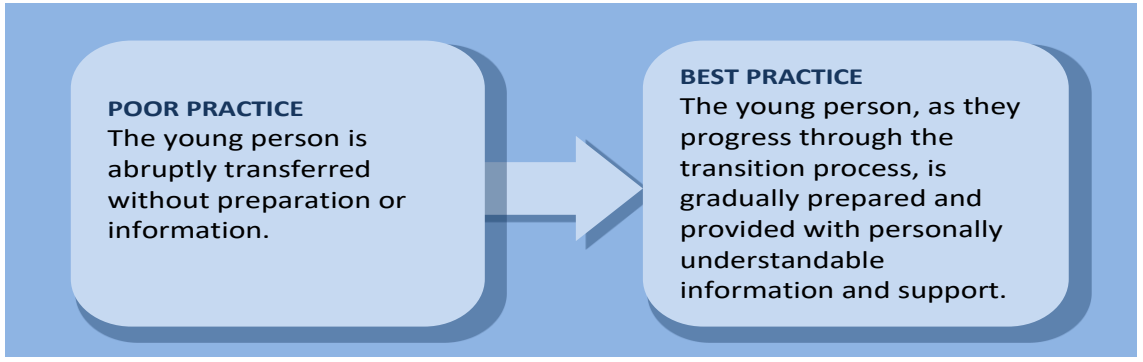
Factor 1

Moving to manage a health condition as an adult



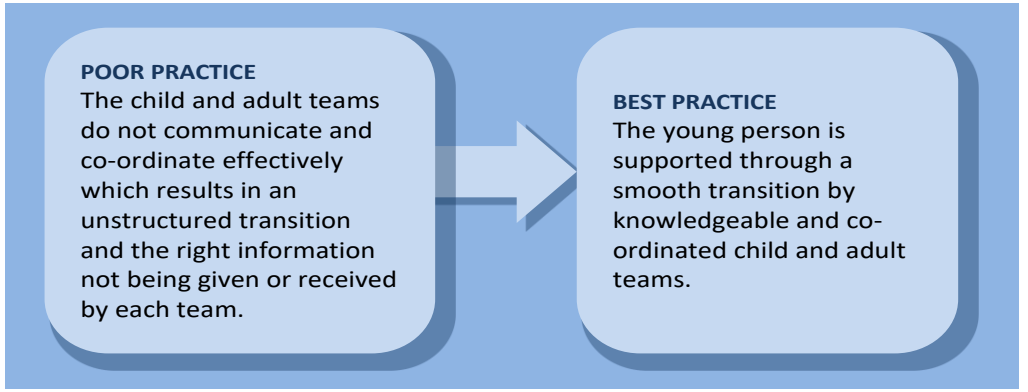
Factor 2

Support for gradual transition



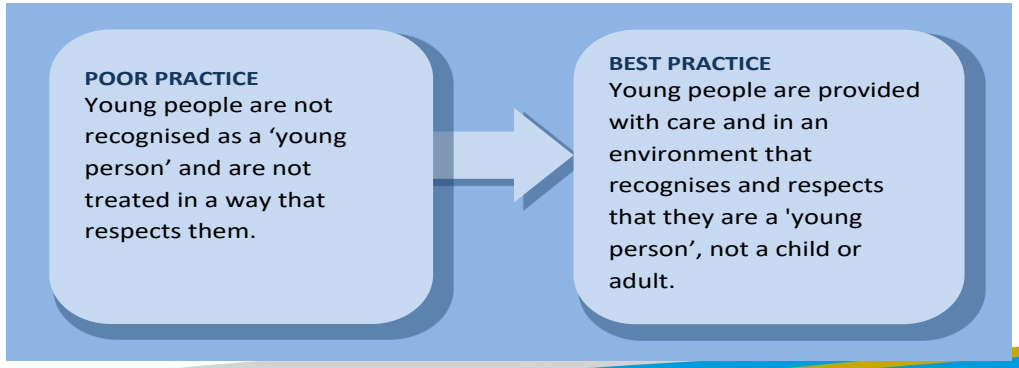
Factor 3

Co-ordinated child and adult teams



Factor 4

Services 'young people friendly'



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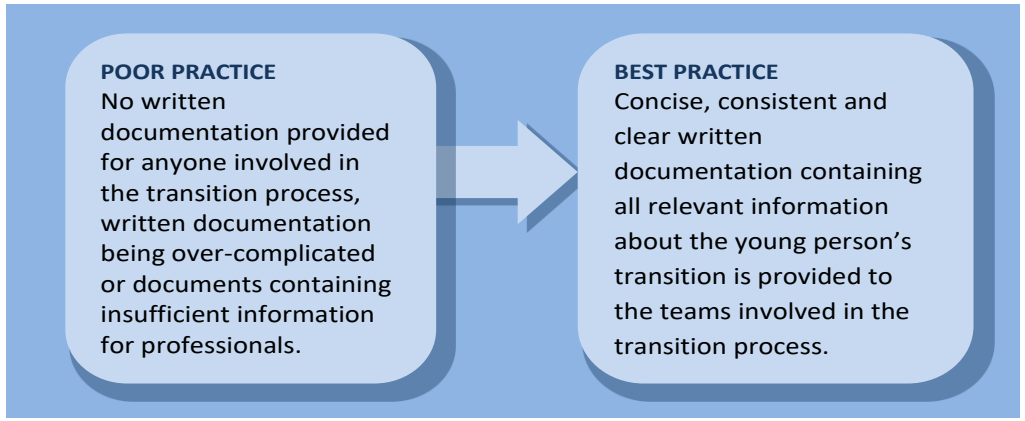
Benchmarking Services

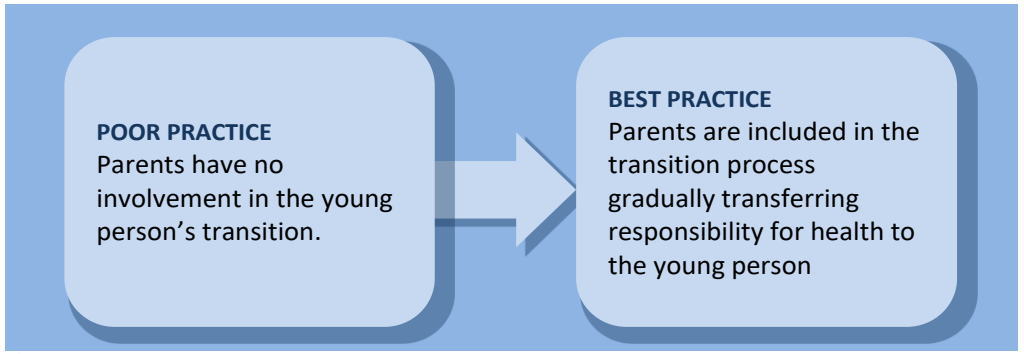
Factor 5

Written documentation



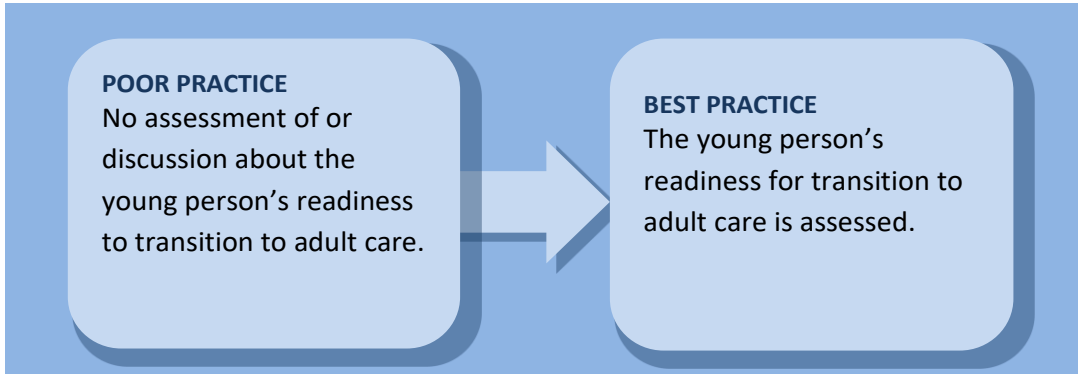
Factor 6

Parents



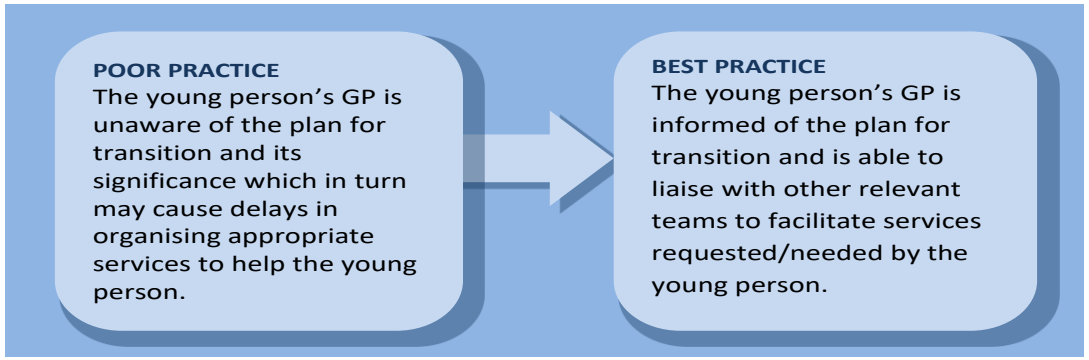
Factor 7

Assessment of 'readiness'



Factor 8

Involvement of the GP.



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The Future State – Developing best Practice Pathways

Define best practice for your service including the You're Welcome Criteria

Use Transition Documentation Tools e.g. Ready Steady Go

Identify and agree new roles and responsibilities

Identify skills / knowledge required to deliver the Future State Pathways

Identify the gaps between current skills and desired skills & knowledge

Create and implement training programs and ensure time is allocated to education

Communicate Good Practice evidence gathered, new roles and responsibilities and Future State Pathways

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Define Future State

Define future state (Including You're Welcome criteria)	• Benchmark service against best practice using the University of Surrey's benchmarking tool	➢ Benchmarking where you're at may affect your stake holder list ➢ What should the service look like regardless of financial constraints, staffing etc..Think of an ideal pathway based on what the patient needs ➢ Roles and responsibilities-agree who is doing what don't just assume ➢ ? SOP for clinic; everyone to follow the same process
	• Define best practice for your service including the use of the 'you're welcome criteria'	➢ Make sure that that gap then doesn't exist in the future state pathway by going through all the benchmarks. If it meets the benchmarks it will meet the NICE guidance standards and the You're Welcome criteria. ➢ Consider clinic observations and assessment against You're Welcome criteria. Will highlight gaps too which then can be closed. ➢ Consider services that might not review annually eg. Cardiac services. Can build in a specific transition appt which may be nurse led.
	• Use documentation transition programme documentation tool, for example; 'Ready Steady Go'	➢ Needs to follow guidelines and deliver best practice but needs to be locally defined to support buy in from staff in addition to making it fit for specific service. ➢ Be specific about age of transition to ensure that this happens rather than saying it will happen across a range of ages. Take into account the needs and wishes of patients rather than just staff assessment of readiness to transition. ➢ Think about how service would like to document transition eg. GUGI, 10 Steps, RSG but some services will have their own where transition may be built into lifelong document. Is any current documentation robust enough if external staff were to review?
	• Develop best practice future state patient pathway for transition	➢ How is this being measured eg. Number of patients/where pts are in transition etc. Normal databases can be adjusted to incorporate new measures rather than replicating work. eg. DNA rates in adult services; ➢ Thinking about pathway, who needs to do what and when? Needs to be agreed otherwise might not happen eg. Transition events, comms, measures etc. ➢ Make sure all people needed to make the changes are involved eg. Business managers, service managers, administrative staff. Think creatively eg. Education settings may be supporters of transition processes.
	• Identify and agree new roles and responsibilities	

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Diagnostic & Solution Design

These are your pathways

Current state mapping: the current state is simply what your transition service looks like at a particular point in time.

To understand the current state of transition we have used;

Brainstorming

Patient pathway mapping

Value stream mapping: looking at the patient pathway, identifying which parts add value to the patient.

Benchmarking (LSBU & service specific)

Future state mapping: the future state is what you want your transition service to look going forward…..this is the '*best practice*' pathway

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Gap Analysis & Implementation

- Comparing current state and future state pathways (including gaps identified in benchmarking)
- Implementing the new aligned roles and responsibilities identified during the mapping process
- Implementation can be a stepped / staged process – if a service can't meet the future state / best practice pathway immediately
- Putting into practice the future state pathway

From experience we know.....most services have delivered future state / best practice pathways as staged implementation.

It can take anything from 6 months to 10 years to achieve best practice

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Training Needs and Gap Analysis

Training needs analysis and gap analysis	• Identify gaps between current state of transition pathway and future desired state pathway • Identify skills / knowledge required to deliver the future state transition programme to patients and families • Identify gaps between current skills and desired skills and knowledge	➢ May be around communication/documentation/SOPs align roles and responsibilities ➢ Knowledge and understanding of the process in addition to specific skills ➢ Consider patients and parents. Look at stakeholders and find suitable way to disseminate information around new process ➢ Need to elicit agreement from staff to take on new roles and responsibilities, use motivational interviewing/coaching skills ➢ Consider attitude in addition to skills and knowledge; do staff understand why YP need something different to adults ➢ Consider HEADSSS assessment ➢ Document action plan which is time bound. Ensure governance around this, who has overall responsibility for this? Regular scrutiny and reporting.

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Communicate

Communicate	• Feedback any good practice gathered from elsewhere	➢ Who are the people that need communicating with? ➢ Consider achieving 'buy-in' from relevant parties
	• Communicate future state	➢ Think about methods of communication for different groups eg. Present paper to exec board, newsletter for families, staff intranet articles etc.
	• Communicate new roles and responsibilities	➢ May be wider stakeholders that need communicating with but are not an immediate part of the process but who will be able to support eg. Charities ➢ Which influential staff are around you to help achieve what you need eg. Buy in from certain staff groups.
	• Communicate work within the project to wider stakeholders	➢ Transformation/Improvement, Patient Experience/PALS and Digital teams can support communication ➢ Consider parent/parent forums teams which might not be directly involved with transition but work with YP. Private healthcare providers eg. LD and autism residential settings.

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Educate and align new roles and responsibilities

Educate and align new Roles and Responsibilities	• Utilise upcoming National Training Programme for Transition when available • Identify trainers / methods of training: face to face, e-learning, practical, shadowing etc.	➢ Ensure education is in line with Core Capabilities for Transition ➢ Implement training programme (clear aims objectives, methods of assessment & timescales) ➢ Ensure time allocated for training

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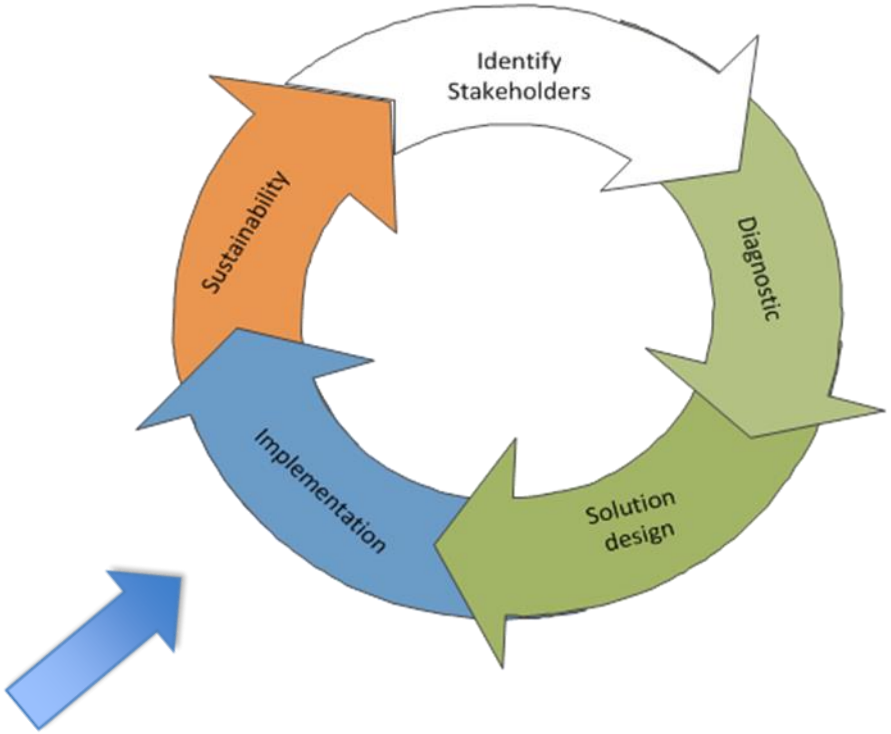
Implementation



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Implement

Implement	• Roll out use of the new patient pathway • Delivery group to support staff in use of the new transition pathway	➢ Build communication strategy around start date and roll out • Consider formal start date for new roles and responsibilities and gian authority for better impact

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Principles of Transition Implementation

Things to consider:

- What are the priorities that have been identified in the Gap analysis?
- Identify what workstreams are required (Leadership, Training & Development, Service Delivery, Pathway Development)
- What skills, knowledge and capacity is required to ensure that the workstreams are enabled – Action Plan
- Who has been identified to lead on each aspect of each aspect of the Implementation Process - Align roles and responsibilities
- What training and education will be required to deliver and embed the Patient Pathways.
- How will the Pathways be communicated with a System wide approach?
- What timeline has been agreed to launch the Pathways? Consider a formal start date for maximum impact ensure robust coms
- How will we know if the pathways are working successfully? - How will you measure improvement)

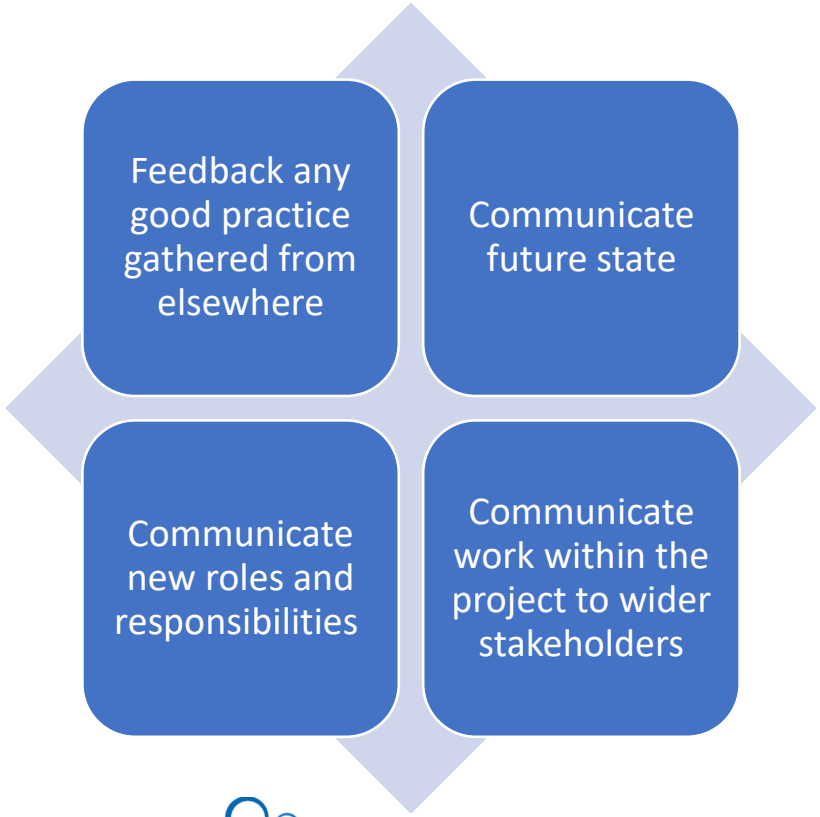
Implementation
- Skills and Knowledge Analysis

Identify skills / knowledge required to deliver the future state transition programme to patients and families

Identify gaps between current skills and desired skills and knowledge

- Align roles and responsibilities
- Consider what documentation / Policies and SOPs will be required
- Knowledge and understanding of the process in addition to specific skills
- Consider patients and parents. Look at stakeholders and find suitable way to disseminate information around new process
- Need to elicit agreement from staff to take on new roles and responsibilities, use motivational interviewing/coaching skills
- Consider attitude in addition to skills and knowledge; do staff understand why YP need something different to adults
- Document action plan which is time bound. Ensure governance around this, who has overall responsibility for this? Regular scrutiny and reporting.

Implementation - Communication Strategy



- Who are the people that need communicating with?
- Consider achieving 'buy-in' from relevant parties
- Think about methods of communication for different groups eg. Present paper to exec board, newsletter for families, staff intranet articles etc.
- May be wider stakeholders that need communicating with but are not an immediate part of the process but who will be able to support eg. Charities
- Which influential staff are around you to help achieve what you need eg. Buy in from certain staff groups.
- Transformation/Improvement, Patient Experience/PALS and Digital teams can support communication
- Consider parent/parent forums teams which might not be directly involved with transition but work with YP. Private healthcare providers eg. LD and autism residential settings.

Implementation
- Training and Education

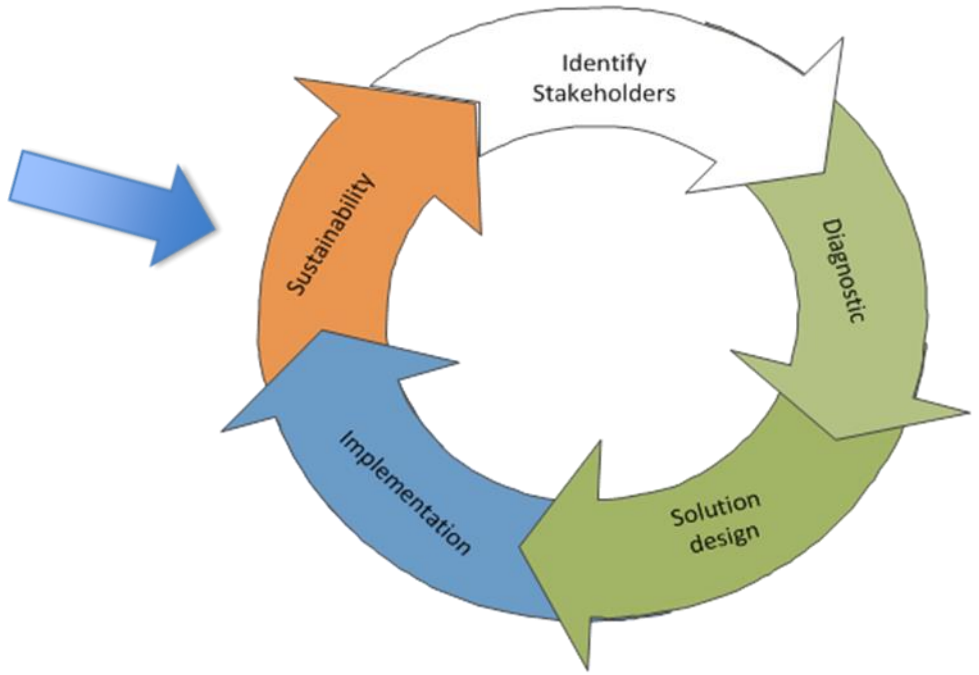
Create	Identify	Implement	Ensure
Create training programme	Identify trainers / methods of training: face to face, e-learning, practical, shadowing etc.	Implement training programme (clear aims objectives, methods of assessment & timescales)	Ensure time allocated for training

Pathway Launch and Implementation

Roll out use of the new patient pathway

- Identify the delivery group to support staff in use of the new transition pathway
- Consider formal start date for new R&R and authority for better impact
- Build comms around start date

Sustainability



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Assurance governance and sustainability

Create audit mechanism (measure of success) and review	• Identify Key Performance Indicators to be used • Agree how, when and who will collect measurement data and set a date to review of findings and pathway • Update and refine pathway if required following audit	➢ Patient experience questionnaires ➢ Need baseline to work from ➢ Consider DNA rates as indicator of success ➢ Look at local measures eg. Diabetes and HB1C; is it affected ➢ Review measures annually at a minimum ➢ PDSA cycle – PLAN>DO>STUDY>ACT ➢ Who is collecting measures? Has this been agreed and are staff members aware (as discussed in Training above) ➢ Further examples of KPI's…….

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Sustainability

In order for the pathway change to remain sustainable it is imperative that there is on-going focus and scrutiny.

This could mean

- Annual review of outcome measures, patient experience & engagement measures.
- Annual pathway design review – Are there any new gaps? Can we anticipate any future gaps?
- Maintaining an MDT approach – thus meaning the pathway / process doesn't breakdown when key individuals move on
- Bi-monthly review of hard data (number of patients, patients over the age of transfer, number of patients with plans in place etc.)
- Spot checks of patient registers

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Transition KPI – Mind Map

National Benchmarks / KPI's

- Standard 1 = Transition planning from 13 years

How many age appropriate YP have started Transition?

- Standard 2 = Annual Health Meeting

How many YP require annual meeting versus how many have been completed?

- Standard 3 = Named Worker

Number of YP who have a named worker identified.
What is there level of engagement?

- Standard 4 = Meeting Adult Practitioner

Have individual services been identified / has an adult physician been identified?
Has the YP had a joint Paediatric / Adult service meeting?

- Standard 5 DNA Process

Measure DNA rate
Has the YP been followed up and offered further appointment?
What is the re-engagement rate?

Whole Organisation Aims / Measures

- Transition Lead Nurse in Post
- Executive Lead Identified
- Transition QI process utilised including regular re-evaluation to ensure sustainability.
- Number of individual service pathways in use versus number required.
- Transition Youth worker in post.
- Patient Experience process in place to allow regular YP feedback (Youth Forum?)
- Governance process – Steering Group, Transition Board etc.

Overall / Generic KPI's for Organisation

- System Wide approach in use. (Are all services using an agreed and consistent process, Care plans, and Communication Tool).
- Is there a program of support in use? (RSG, GUGI, 10 Steps etc)
- How many Young People have a Transition Plan?
- How many YP have joint involvement with paediatric AND adult services?
- How many pathways are required for the YP versus how many are actually in use?
- Has the YP got a named worker?
- What is the DNA rate?
- What is the number of unplanned admissions to ED / inpatient units.

Service Specific KPI's

Examples:

- Diabetes – HBA1C, admission to ED / Ward/ DKA episodes
- CF – Lung Function, infection rates
- Renal / Liver – Graft retention, Transplant fails, Function tests.

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South Thames Paediatric Network
Transforming Healthcare for Children and Young People

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Transition National Key Documents and Guidelines

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An introduction to HEEADDESSS

Nigel Mills

Burdett Regional Nurse Advisor (London)

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HEEADESSS-what is it?

Tool for:

- Communication
  - An interview prompt
  - An opportunity to develop a relationship and rapport
- Holistic assessment
- Psych-social assessment
  - Risks and strengths
- A guide to possible future interventions

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HEEADSSS

Home
Education and employment
Eating
Activities
Drugs
Sexuality
Suicide and depression
Safety (savagery)

(Originally Goldenring & Rosen, 2004)

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An introduction to…

Got Transition (North America)
Trapeze (Sydney)
Melbourne

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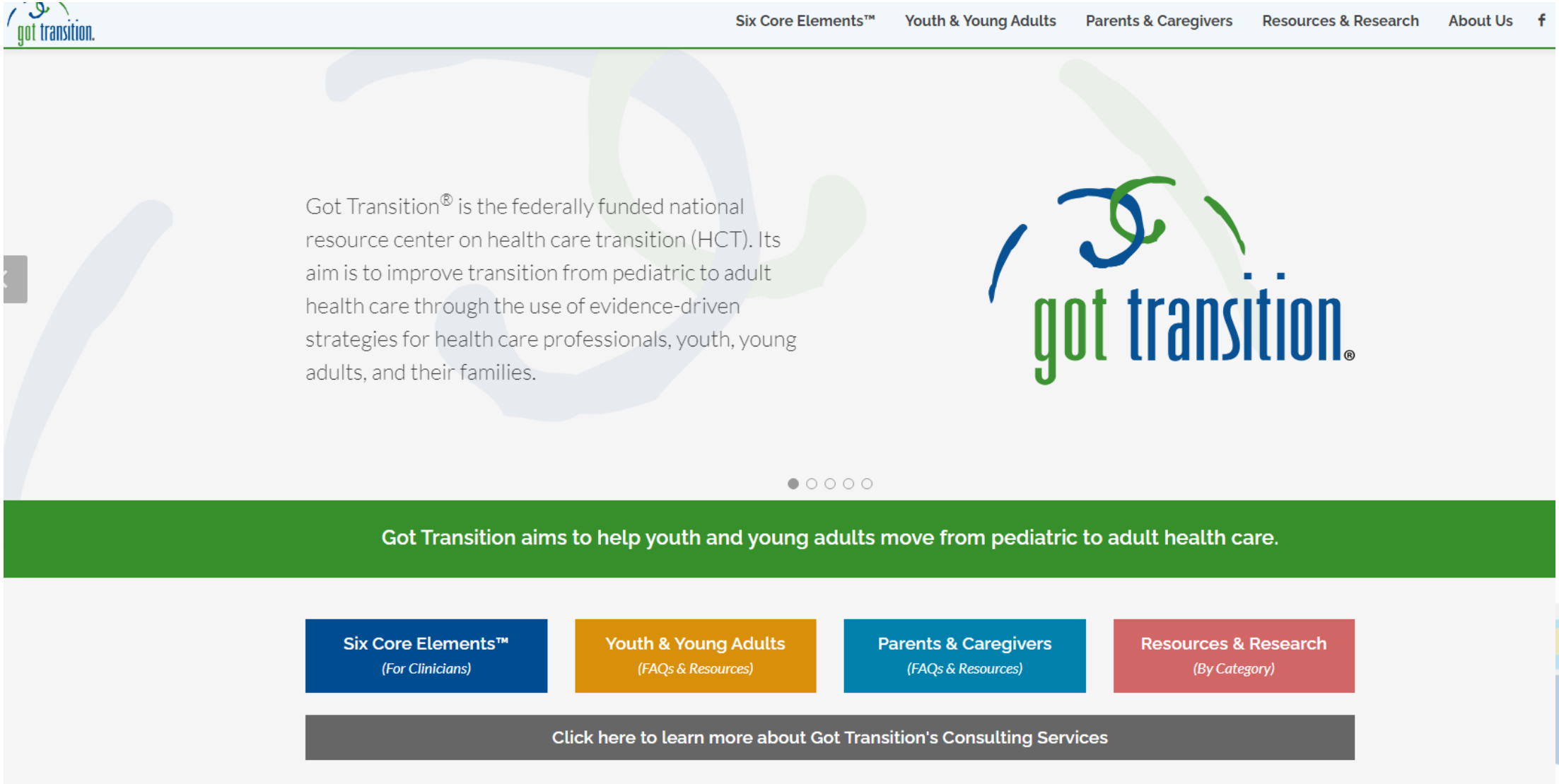

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Are you transitioning to adult healthcare services?

Young people who have chronic conditions and disabilities need to transition from children's healthcare to adult health services. **The ACI Transition Care Service is here to support you.**

What we do

There are differences between children's and adult health services and some young people aged between 14 and 25 years need extra support.

- We offer a confidential and free service that is part of NSW Health.
- Transition care coordinators and support workers help young people, families, carers and clinicians during transition.

You will be given the details of your care coordinator and support worker.

Tell them if you want to be contacted via phone, text or email so they know the best way to reach you.

We help by

- Working with your healthcare team to find suitable adult health services
- Creating a transition plan that contains important information
- Supporting you to get referrals and make appointments
- Going with you to your first appointments, if needed
- Sharing resources with you
- Providing updates to your healthcare team about your transition

NSW GOVERNMENT | AGENCY FOR CLINICAL INNOVATION

What we can't do

While we would like to help with everything, there are some things we can't do, such as:

- make appointments on your behalf, however, we can help you learn how to do this
- complete paperwork and provide supporting documents for NDIS or Centrelink.

NSW GOVERNMENT | AGENCY FOR CLINICAL INNOVATION

Contact us

We'll contact you after your adult health appointments. You can also call us if you need help.

When you've met with your adult health services and feel comfortable, we will discharge you from our service. But you can still contact us until you turn 25.

The contact details for ACI transition care coordinators are on our webpage.

Young people, carers or clinicians can refer to our service.

All we require is a referral form with the young person's consent.

Trim ACI/D22/2684 | SHPN (ACI) 221130 | ACI6955 [12/22]

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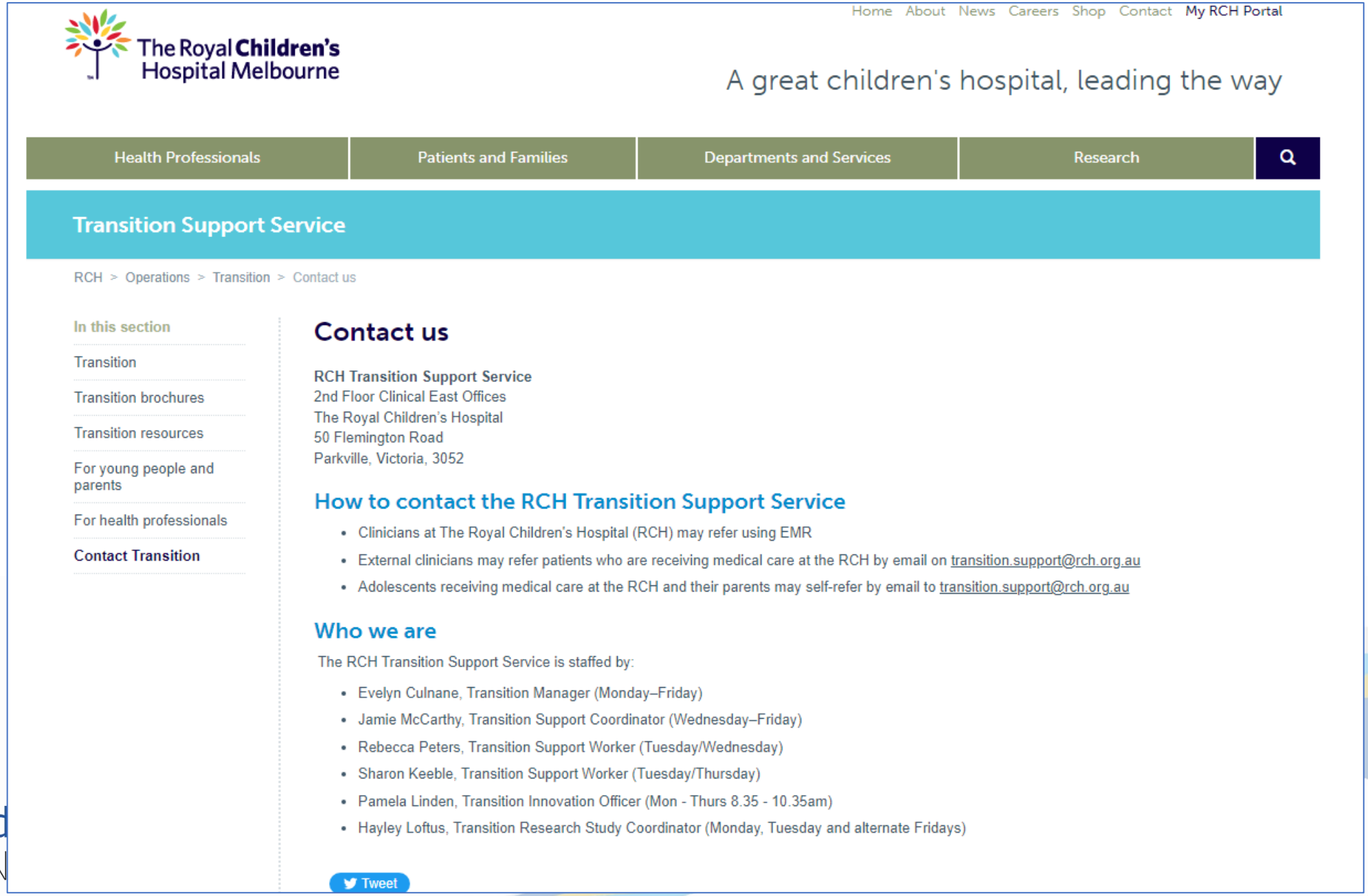

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Slido 1

What transition tool do you currently use?

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Growing Up Gaining Independence (GUGI)

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GROWING UP, GAINING INDEPENDENCE

- Simple framework to enable clinicians to encourage and support young people to develop the skills, knowledge and understanding associated with emerging adulthood, and to help prepare them for adult specialist healthcare if necessary (transition).
- Designed to work with other tools (RSG) or established good practice
- Can be used as a stand-alone tool

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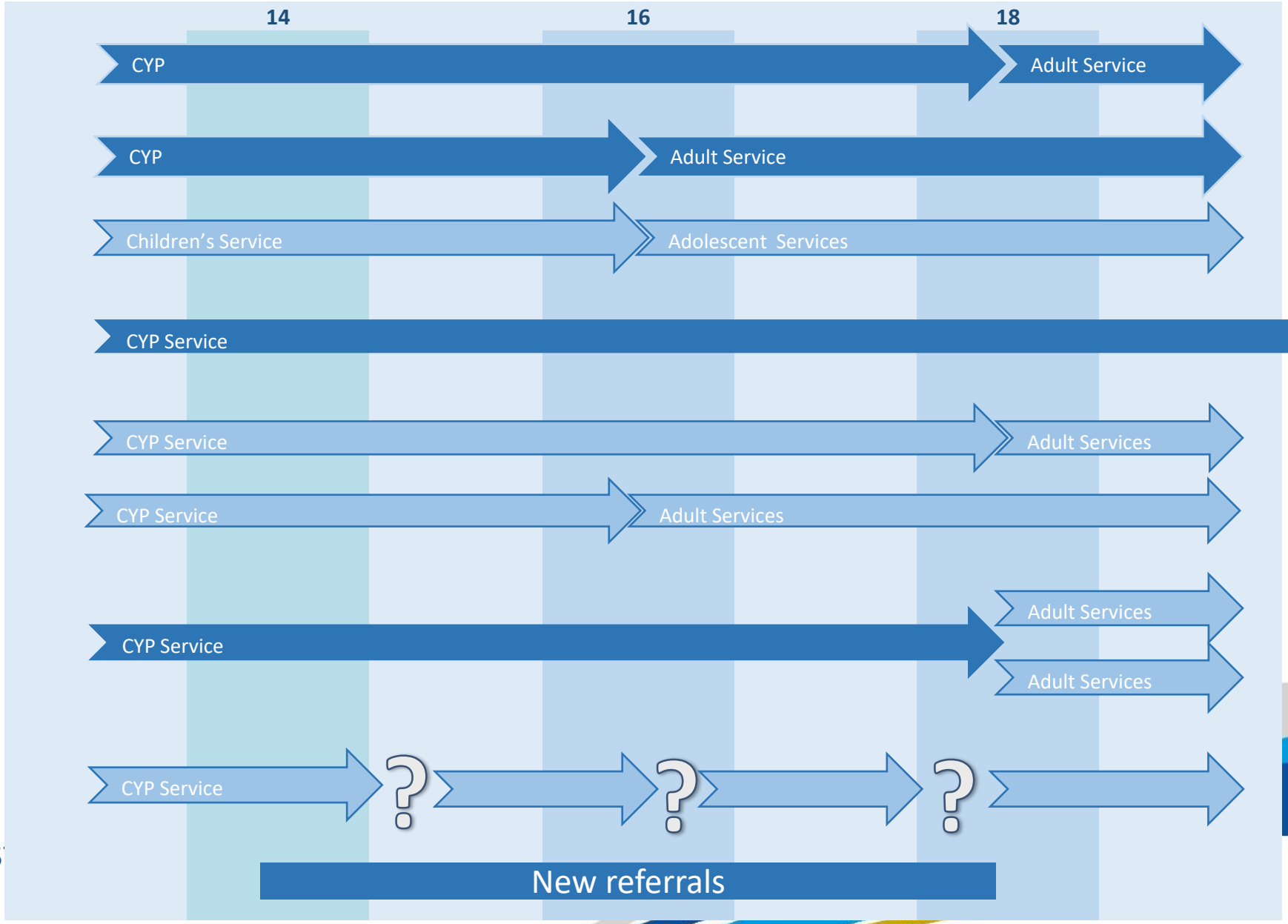

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An introduction to Ready Steady Go Hello

Nigel Mills

Burdett RNA (London)

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RSGH

- Series of questionnaires/statements to prompt discussions
- Used to develop individualised Transition Plan
- Free!
- Online or paper
- Excellent resources
- Widely used
- Suitable for Paeds and adult services

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Introduction booklet

What is transition?

In healthcare, we use the word "transition" to describe the process of preparing, planning and moving from children's to adult services.

Transition is a gradual process that gives you, and everyone involved in your care, time to get you ready to move to adult services and discuss what your healthcare needs as an adult are likely to be.

This includes deciding which services are best for you and where you will receive that care.

Transition is about making plans with you - and not about you.

We understand that moving away from a team of doctors and nurses that you have been with for many years can be scary but hopefully, by getting involved in the transition process, you will feel more confident and happier about the move.

Why do I have to move?

As you get older, you will find that some of the things you want to discuss or some of the care you might need is not properly provided by our children's services.

Adult services are used to dealing with all sorts of issues that may arise, such as higher education, travelling, careers and sex.

You may also find that you would prefer to be seen in a more grown-up environment, rather than the usual children's departments or wards.

When do I have to move?

There is no exact time that is right for everyone.

The purpose of this leaflet is to get you thinking about moving on and preparing for it.

Your doctors and nurses may have an idea about when they feel that you might be ready but it is important that you are involved in that decision.

Can I choose where I move to?

Part of the transition process should be helping you to look at where your ongoing healthcare needs can best be met and how this will fit in with your future plans.

Your consultant or family doctor (GP) will be able to give you information to help you make the best decision.

If there is a choice of places, it is a good idea to visit all of them and then decide which is best for you.

Who can help me get ready?

Your healthcare team will be able to give you information and support about moving on.

They can help you get ready for adult services by:

- Teaching you about your condition or illness, its treatment and any possible side effects
- When you are ready, seeing you on your own for part of the clinic appointment and working towards seeing you on your own for the whole clinic appointment
- Making sure you know when to get help and who to contact in an emergency
- Helping you understand how your condition or illness might affect your future education and career plans
- Making sure you know about the support networks available
- Making sure you understand the importance of a healthy lifestyle, including exercise, diet, smoking and sex.

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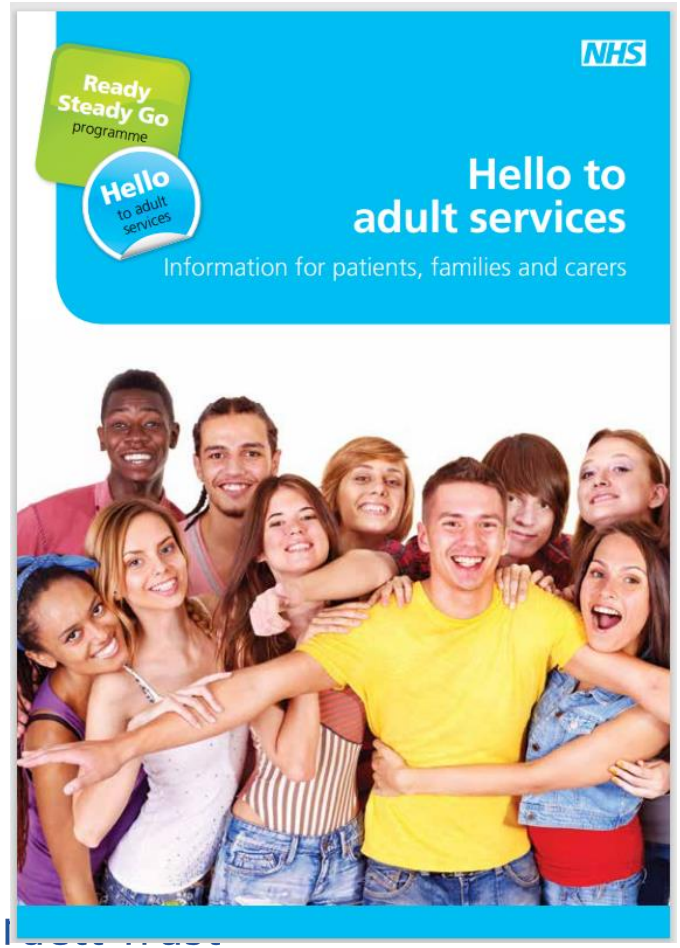
Hello



We understand that learning you have a long-term condition can cause anxiety and be overwhelming.

We have developed the 'Hello to adult services' programme to help support you and help address any concerns you have.

Who is it for?
You, if you have been diagnosed with a long-term condition.

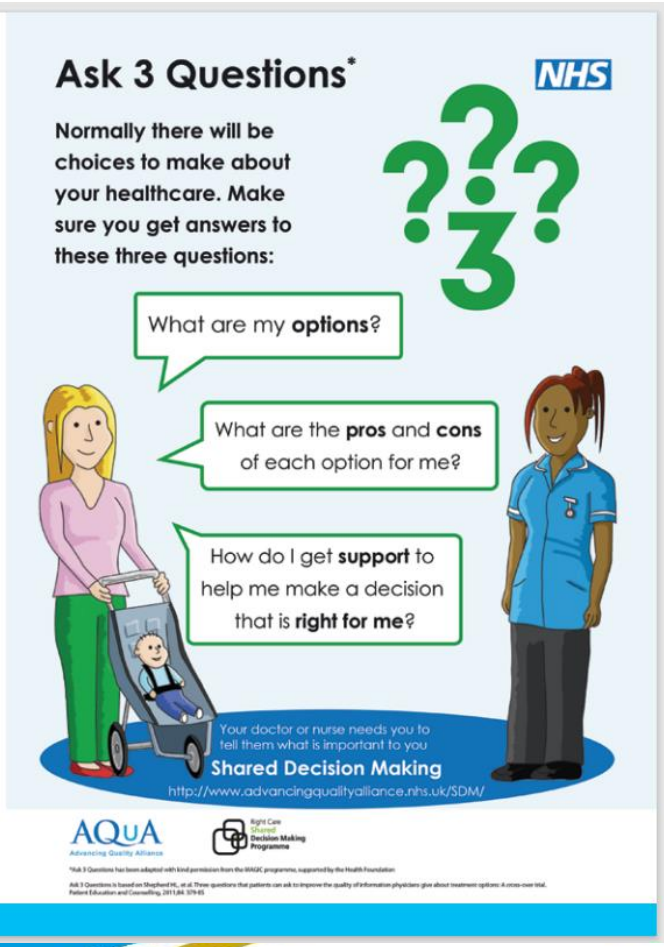
What is it?
A programme to help you gain knowledge and skills to manage your condition.

Why?
So you have the knowledge and confidence to manage your condition and are supported through the process.

How?
Your team will help you:

- **manage** your condition
- **learn about** your treatment
- **gain the confidence** to ask questions and be involved in decisions about your care
- know when to get help and **who to contact** in an emergency
- **stay informed** about any support networks available.

Talk to your team about how you feel and any questions or concerns you might have. Information about the programme can be found at **www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Hello-to-adult-services.aspx**



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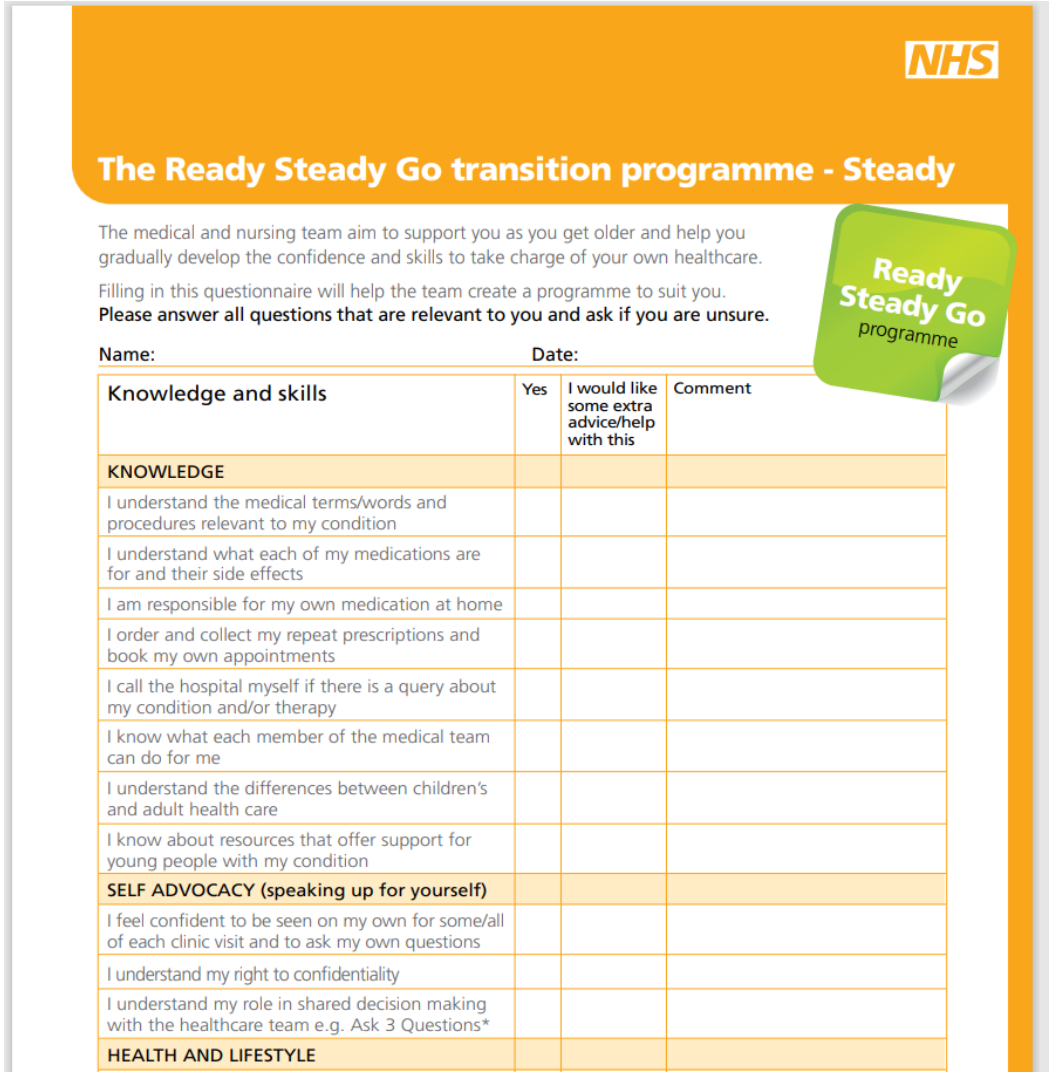

NHS

The Ready Steady Go transition programme - Steady

The medical and nursing team aim to support you as you get older and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.
Please answer all questions that are relevant to you and ask if you are unsure.

Ready Steady Go programme

Name: Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I understand the medical terms/words and procedures relevant to my condition			
I understand what each of my medications are for and their side effects			
I am responsible for my own medication at home			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
I know what each member of the medical team can do for me			
I understand the differences between children's and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own for some/all of each clinic visit and to ask my own questions			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions*			
HEALTH AND LIFESTYLE			

- 8 themes
- 35 statements

- NB-don't rely on answers-they are a gateway to discussion

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Transition Plan

- Used to develop an individualised Transition Plan
  - Identify with YP where they need input/support
  - Plan how to provide input/support

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Future plans and support

Contact	• Louise Porter the National Transition Lead Nurse will remain in post until November to develop a handover strategy.
Handover	• Each Region will provide handover documents containing mapping for transition which will provide a situation analysis for transition within organisations / providers.
Resources	• A national single point for Transition Resources is proposed which will include The Burdett Website and NHS Futures pages.

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Thank You

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