South Thames Paediatric Network
Transforming Healthcare for Children and Young People

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)

Nigel Mills

Burdett Regional Nurse Advisor for Young People's Healthcare Transition (London)

Session 1 of 6

NHS The Leeds Teaching Hospitals NHS Trust

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

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The Burdett National Transition Nursing Network

NHS The Leeds Teaching Hospitals NHS Trust

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

An Introduction to the Network
National and Regional Updates
National Guidelines and Standards for Transition
Developing Best Practice Transition Services

Stella Carney

Burdett Regional Nurse Advisor for Young People's Healthcare Transition

(South of England)

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Introduction

- Under 18s represent nearly 20% of the population and it's estimated that more than 40,000 children are living with life threatening illness.

CQC From the Pond to the Sea. (2014)

- In a typical NHS Trust serving a population of 270,000, approximately 100 young people with a long term condition requiring secondary care, reach the age of 16 years each year…….
- This means that because Transition should extend over a minimum of seven years, the number of young people actually in Transition at any time is approximately 700 in the typical NHS Trust.

National Institute for Health & Care Records (May, 2019)

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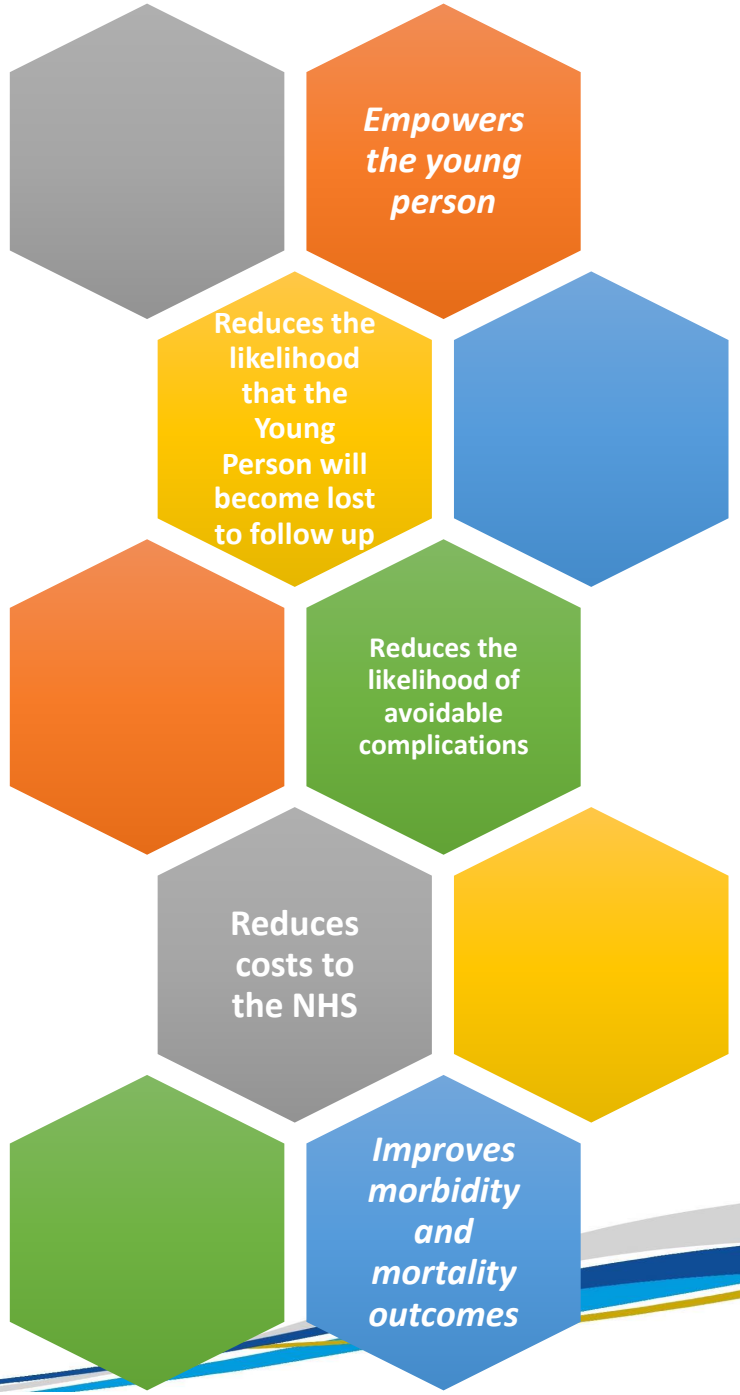
Transition

Effects & Benefits



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Transforming Healthcare for Children and Young People

Transition

Session 1 - Agenda

- Burdett National Transition Nursing Network - purpose & plan.
- National & Regional progress to date.
- National Standards – Quality Statements – What Best Practice looks like.
- Transition – The Young Person's Voice
- Challenges of delivering an effective and sustainable Transition Service
- The Burdett Offer – How we can support organisations
- Burdett Offer – 1:1 Coaching
- Burdett Offer – Introduction to the Burdett Transition QI Process
- Next Steps – Call to action.

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Aim and Objectives for Transition Collaborative Events

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

- 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.

Burdett National Nursing Network

- Who we are
- Plan and Purpose
- RNA Roles

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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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The Plan

Three year national project funded by Burdett Trust (2019/20 - 2023)

Research Team - Transition Benchmarks (University of Surrey) Evaluation of project

- Map where transition is happening
- Create database of Transition Leads and contacts
- Understand the current state of transition across England for all healthcare organisations
- Share best practice examples
- Support implementation of Transition Quality Improvement model

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The Purpose

- 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.

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Project Scope

- Working with organisations from all the stakeholder groups
    - Hospitals
    - Primary care
    - Community
    - Palliative care / hospices
    - Mental health
    - Learning disabilities

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Regional Nurse Advisors (RNAs)

Roles & Responsibilities:

- Set up and lead regional networks (4 regions of England i.e. North, Midlands, London, South)
- Support individual leads and champions within organisations to implement the agreed transition model
- Provide a co-ordinated and unified approach to transition
- Map transition work across the region; identify existing service provision, with the intention of developing regional & national service directories
- Contribute to a national transition toolkit
- Support research and data collection
- Advise on transition training & education
- Support NHS E Transition Collaborative work

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Burdett National Transition Nursing Network Measures

What's been achieved Nationally

Regional achievements and activity

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Burdett National Transition Nursing Network

Purpose

- To improve care of young people in transition
- To influence care of all young people

Impact

- Working with 384 organisations
- Pathways in production / transition lead roles increased

Influence

- Working in partnership with NHS E
- Removing barriers / setting standards (service specs)

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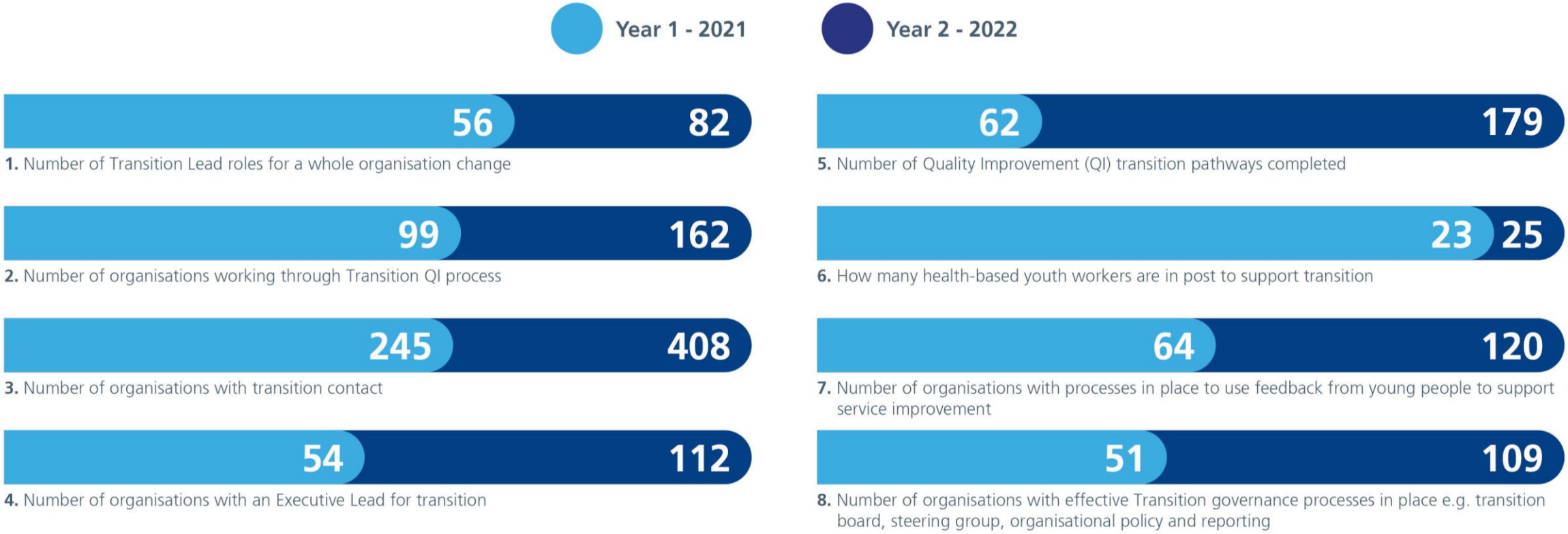
National Transition Overview



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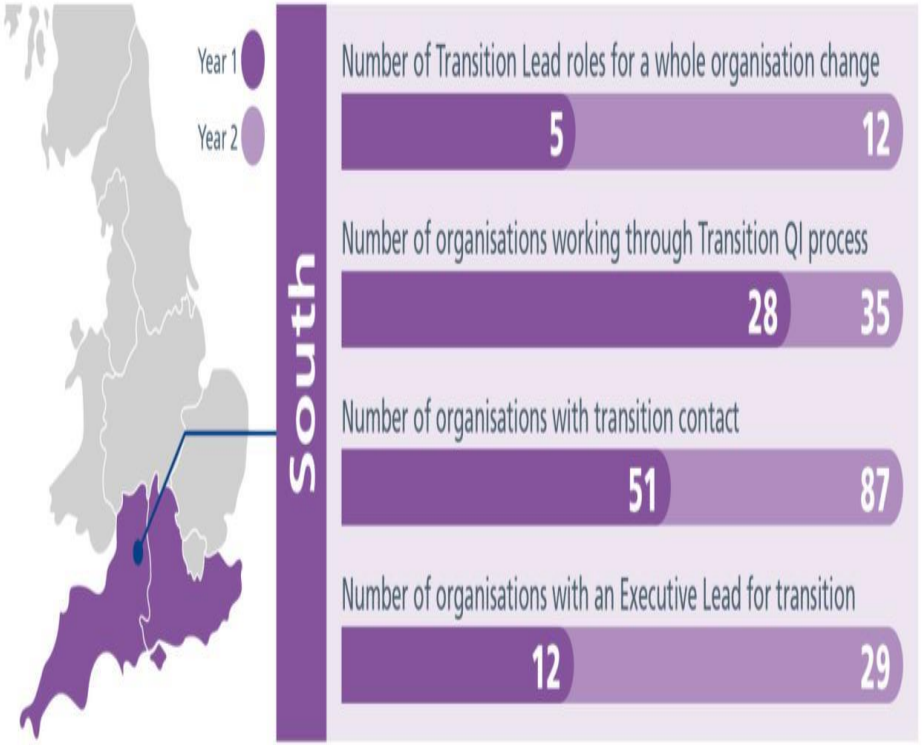
Regional Transition Overview - South



Working with a number of new organisations including Networks across the Region.

Transition leads across the region increased by a further 2 in the past 2 months to 14.

Increased the number of individual Transition Contacts from 123 to 182 in a 5 month period

Ongoing provision of 1:1 support to Transition Leads to work through the Burdett QI process

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Regional Transition Overview - London

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Transition Best Practice – What 'good' looks like…..what 'great' can be

- **National Guidelines**
- **Quality Statements**
- **Aspiring to gold standards**

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Transition Best Practice

- What does good Healthcare Transition mean to you?
- What do you think are the benefits of a good Transition Process?

- Please go to slido.com

Enter code: 3534807

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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 should prepare Young Adults for all aspects of their lives including: Health and lifestyle, daily living, school and their future, social aspects and managing emotions.

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NICE Transition Guidelines NG43 (2016)

Transition from children's to adults' services for young people using health or social care services

- '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.

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

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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Effects of Good Transition

- **Empowers the young person**
- **Reduces the likelihood of avoidable complications**
- **Reduces the likelihood that the Young Person will become lost to follow up**
- **Reduce costs to the NHS**

- ***Improve mortality and morbidity***

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

NHS The Leeds Teaching Hospitals NHS Trust

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

Nigel Mills

Burdett Regional Nurse Advisor for Young People's Healthcare Transition (London)

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The Young Person's Voice

- Not simply about hearing young people's voices but those of their families and carers as well
  - not forgetting siblings
- Every transition and transition experience is unique to each individual young person and their family
  - each will have their own tale to tell
- Can have a long-term impact on future relationships with all healthcare

What young people feel about poor Transition and what they want from Transition Services

- A failure by us
- A poor transition is something that has already happened to them
  - There's no 2nd chance for us to prepare them

    'They didn't tell me that…'

  - There's no 2nd chance for their 1st experience with adult services

    'They told me that…'
- Clear communications
  - With them
    - What? When? Who? How? Where?
  - With the adult team
    - Confidence that the adult team knows about them
    - Worried about falling through a gap

Transition - Challenges

- What are the biggest challenges in developing and providing effective and sustainable Transition Services for Young People?

- Please go to slido.com

Enter code: 3534807

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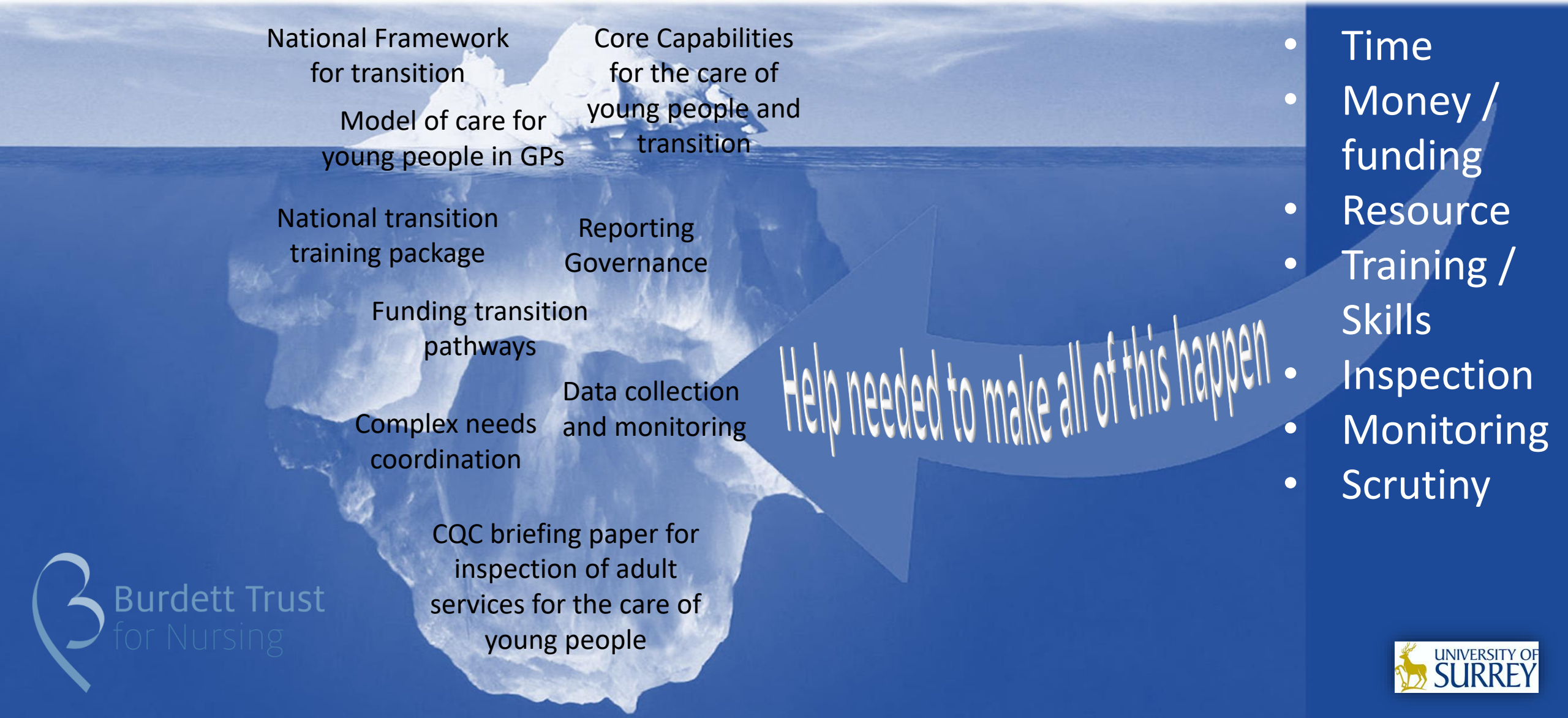
Challenges of Building an Effective and Sustainable Transition Service



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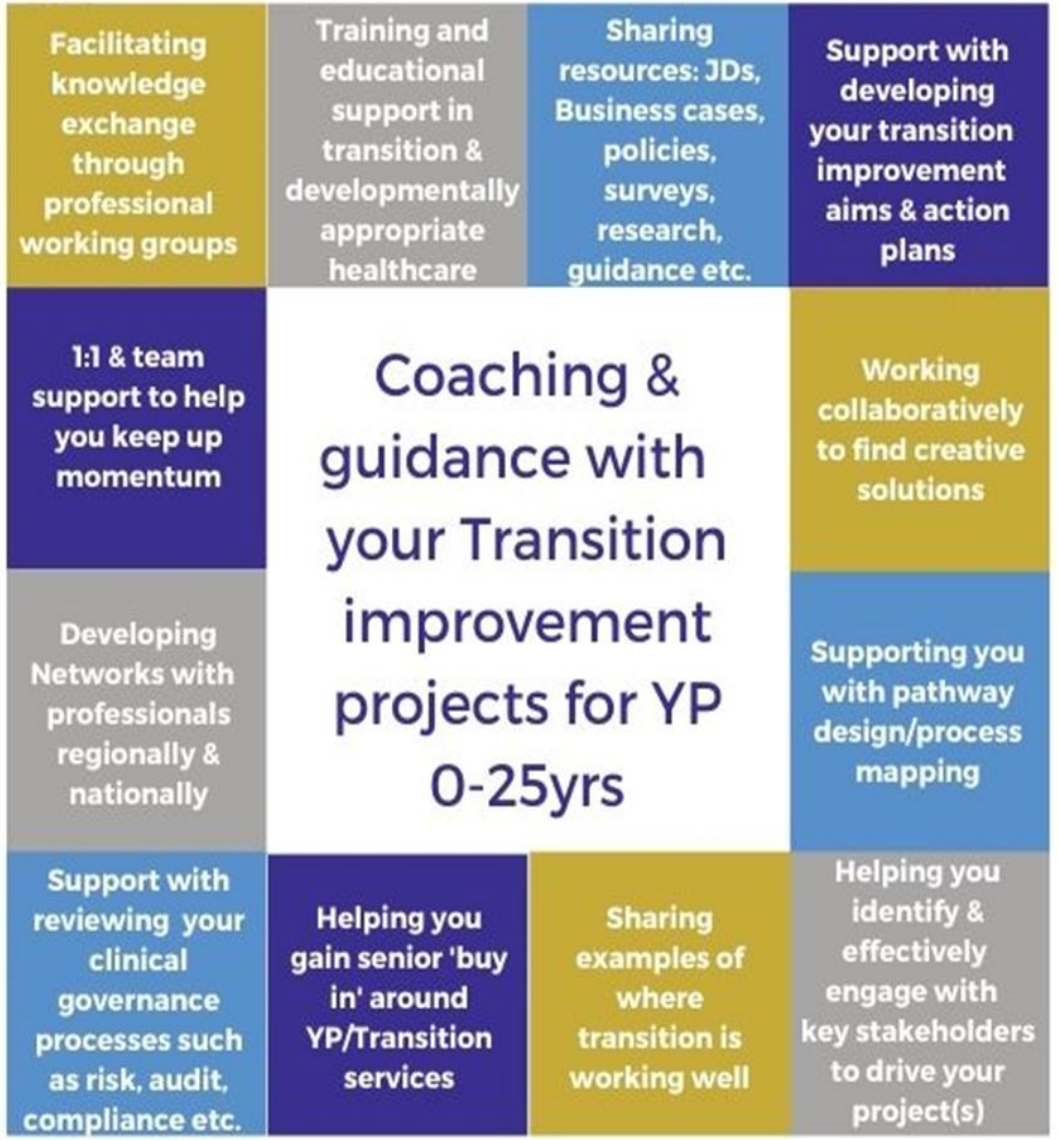
Burdett Support

The ‘Cube’ outlines the sort of help we can offer you

- Individually
  - 1:1 support for Transition Leads
- As part of a team/service/organisation/network



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Networking

- Quarterly regional Network events
- Guest speakers from all stakeholder groups
- Regional & national updates
- Sharing resources
- Networking with other teams across the region
- Opportunity to share challenges & successes
- Hear about events coming up
- Recharging those ‘transition QI’ batteries!

- Community of Practice Events
- National Transition Conference

TRANSITION NETWORK: REGION: SOUTH

NHS Somerset NHS Foundation Trust

DATE: 26.01.2021

Chair: Lucy Duncombe
Regional Nurse Advisor: South East & South West

Email: Lucy.Duncombe@SomersetFT.nhs.uk
Number: 07468 701841

Twitter: LucyDuncombeTST@LucyDuncombe2

1 INTRODUCTION: THE BURDETT NATIONAL TRANSITION NURSING NETWORK

Project aims:
- Improve transition and health outcomes for young people across England
- Map transition across England, understanding the current state across healthcare organisations
- Share the QI model, supporting individual organisations/teams with it's implementation

Regional Network aims:
- Contacts and connections with MDT and AHP colleagues across the region
- Safe and inclusive platform providing opportunity to discuss challenges and explore solutions
- Share fresh ideas, new perspectives, best practice examples, tool and documents
- Re-charge your QI & Transition 'batteries'!

2 CURRENT CHALLENGES...

Impact of COVID-19 is clear across acute & community services in the SE & SW:
- Escalating intensity of current clinical pressures
- Re-deployment of staff
- Dependence on virtual platforms

But alongside this come real positives:
- Rapid QI work, empowering teams to work differently
- Staff learning new skills & working with other teams trust-wide
- Opportunity to rapidly improve our digital systems

Specific impact of Covid-19 within CYP care:
- Increase in the number of virtual clinics during Covid-19 has been beneficial but also raises some issues for transition clinics; virtual clinics should be offered as an option but not a default for all YP
- Safeguarding risks with services being predominantly virtual. *See attached Safeguarding Policy shared to provide support/guidance*
- Initial challenges around engagement & reliability of virtual clinics
- Delayed transfer to adult services - with increasing backlog of appt's
- Access to existing youth groups/forums with increased use of virtual peer support

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The Burdett National Transition Nursing Network

NHS
The Leeds Teaching Hospitals
NHS Trust

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 Transition Quality Improvement Model

Stella Carney

Burdett Regional Nurse Advisor for Young People's Healthcare Transition

(South of England)

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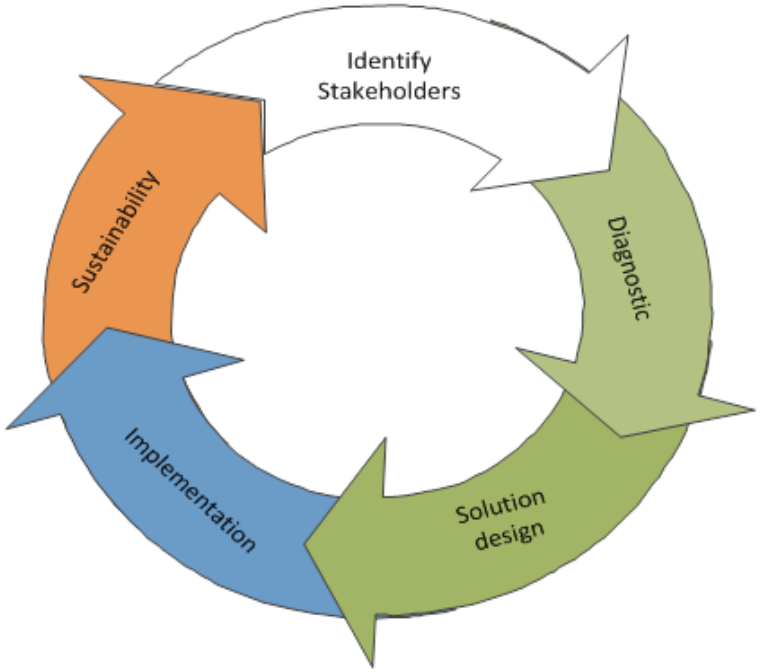
The Burdett Process for Improvement



- Stakeholders
- Diagnostic
- Solution design
- Implementation
- Sustainability

A structured way of approaching improvement

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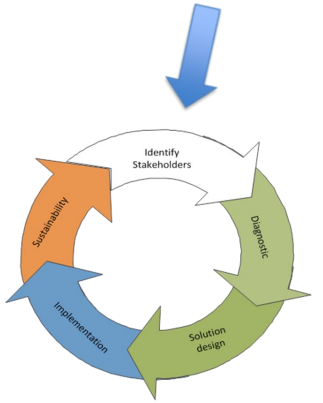
The Burdett Transition QI Process - Stakeholders

A stakeholder is any individual or group with an interest or influence over your transition pathway

These lists are utilised to identify barriers and enablers and to devise a communications plan setting out what information needed to be given to which groups & individuals, and how.

- Primary, secondary & tertiary care partners (child & adult services)
- Community services
- ICB's / Specialist Commissioners
- CEO / Directors / Directors of Nursing
- Third sector



Our experience tells us this can be upwards of 30 individuals & groups

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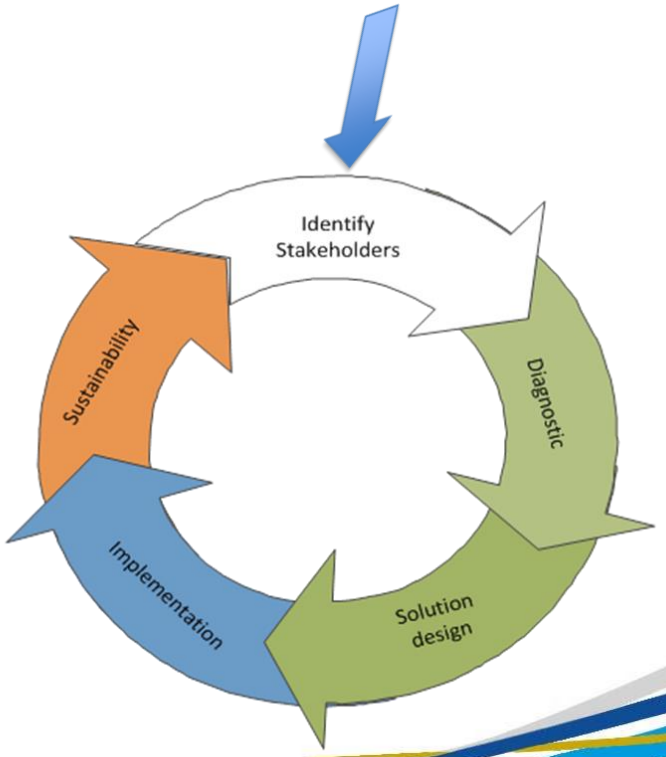
The Burdett Transition QI Process - Stakeholders

Once you have identified your overall key stakeholders the next stage is to:

- Identify the Key Stakeholders for Transition within each of your organisations services, including both Paediatric AND Adult Services
- Create a Stakeholder Analysis to identify who we need to involve, to what level and how often.



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Healthcare Transition

Stakeholder Analysis Grid

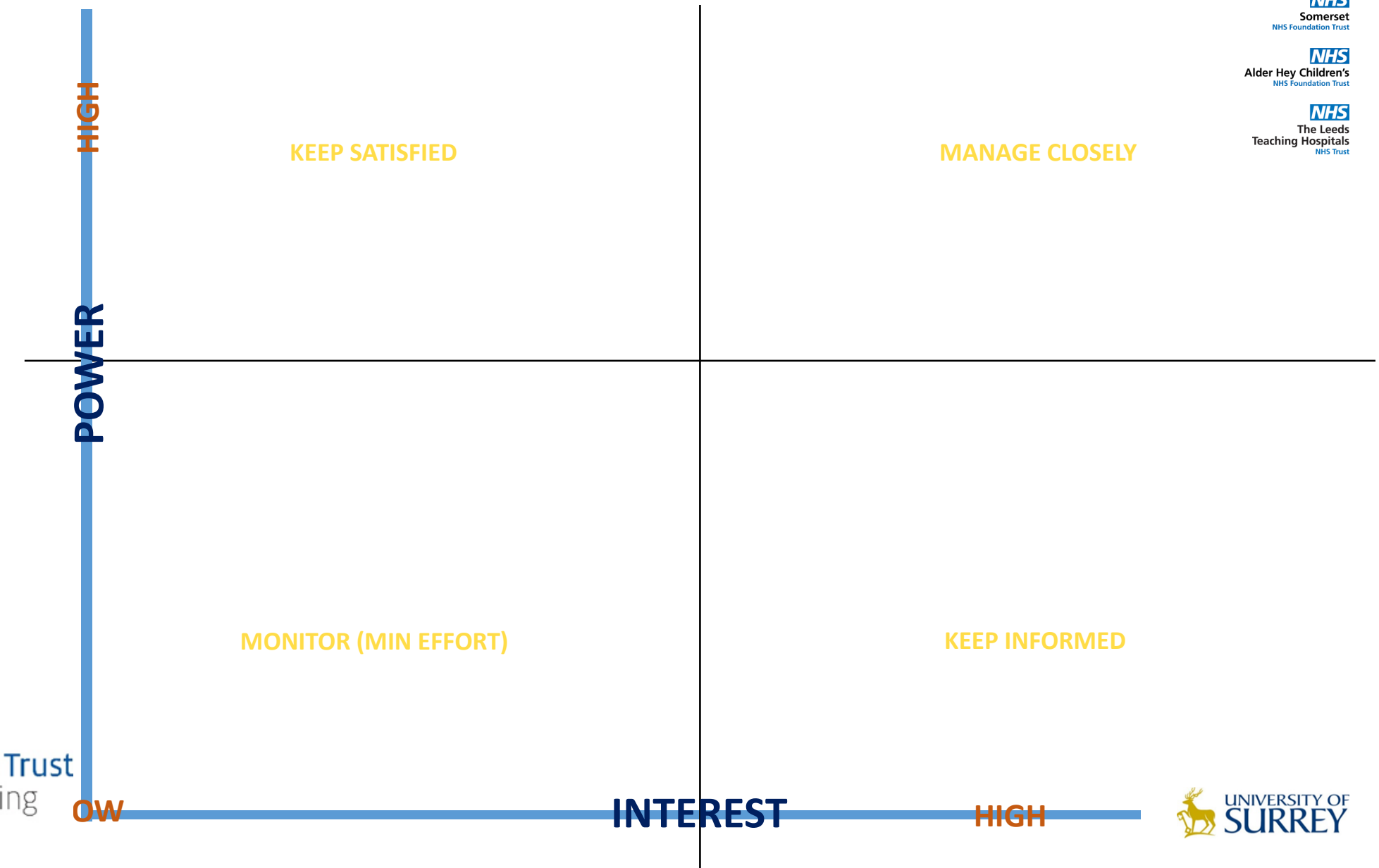
NHS University Hospitals Birmingham NHS Foundation Trust

NHS Imperial College Healthcare NHS Trust

NHS Somerset NHS Foundation Trust

NHS Alder Hey Children's NHS Foundation Trust

NHS The Leeds Teaching Hospitals NHS Trust



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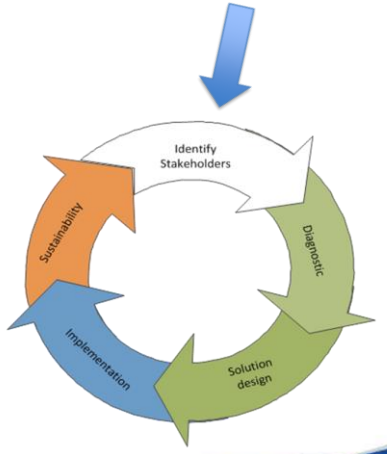
Burdett Transition QI Process - Stakeholders

Once you have identified your overall key stakeholders the next stage is to:

- Identify the key Stakeholders for Transition within each of your organisations services, including both Paediatric AND Adult Services
- Complete a Stakeholder Analysis to identify who you need to work with to influence your service development
- Create focus group to assist the delivery group (Advisory / Steering Group)
- Create delivery groups for the project workstreams (e.g for each service)



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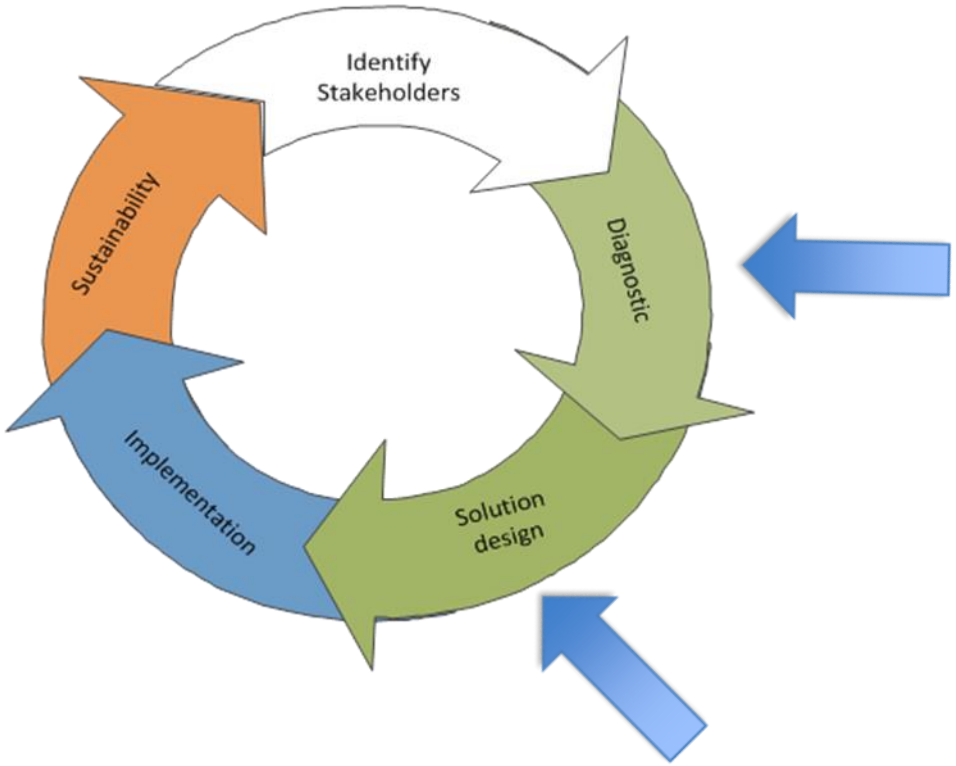
Burdett Transition QI Process - Diagnostic and Solution Design



- Understanding the current state of Transition
- Gathering good Practice from elsewhere
- Defining the future state

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Burdett Transition QI Process - Diagnostic and Solution Design

Mapping Process

Current State
What does the Service look like now?

Mapping Your Service

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


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orchid
Great Ormond Street Hospital for Children NHS
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A guide to using the benchmarks for transition

Research Team
Professor Faith Gibson, Professor of Child Health and Cancer Care, Great Ormond Street Hospital for Children NHS Foundation Trust and University of Surrey.
Susie Aldiss, Researcher in Child Health, University of Surrey.
Dr. Hilary Cass, Paediatric Neurodisability Consultant, Guy's and St Thomas' NHS Foundation Trust.
Professor Judith Ellis, Chief Executive Officer, Royal College of Paediatrics and Child Health.
Tanya Pettigrew, Service User.
Laura Rose, Adolescent Clinical Nurse Specialist, University College London Hospitals.

This work was supported by Burdett Trust for Nursing

Version 1, July 2016

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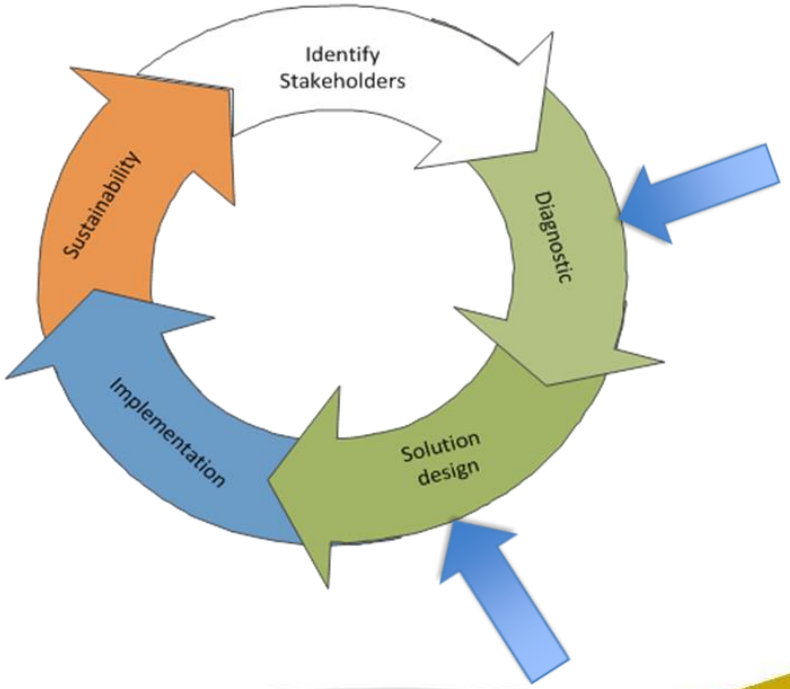

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Burdett Transition QI Process - Diagnostic and Solution Design

London South Bank University · orchid · Great Ormond Street Hospital for Children NHS · University of Surrey

A guide to using the benchmarks for transition

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Version 1, July 2016

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Solution Design:
Developing patient pathways:

Value stream mapping: looking at the patient pathway, identifying which parts add value to the patient.
Benchmarking (National, local & 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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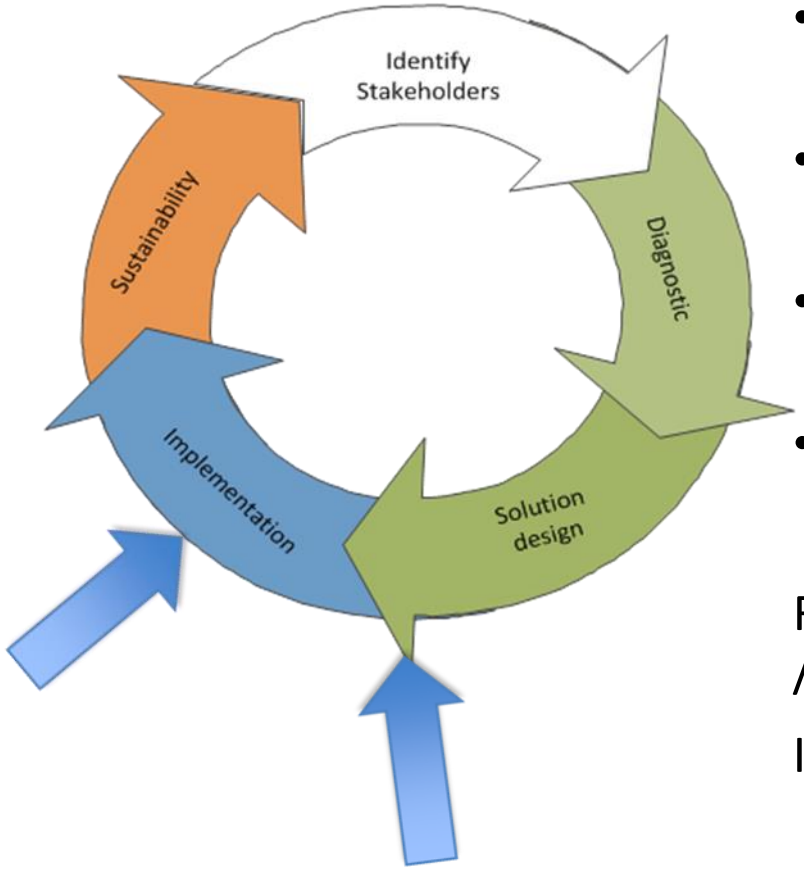
Burdett Transition QI Process – Gap Analysis and Implementation



- 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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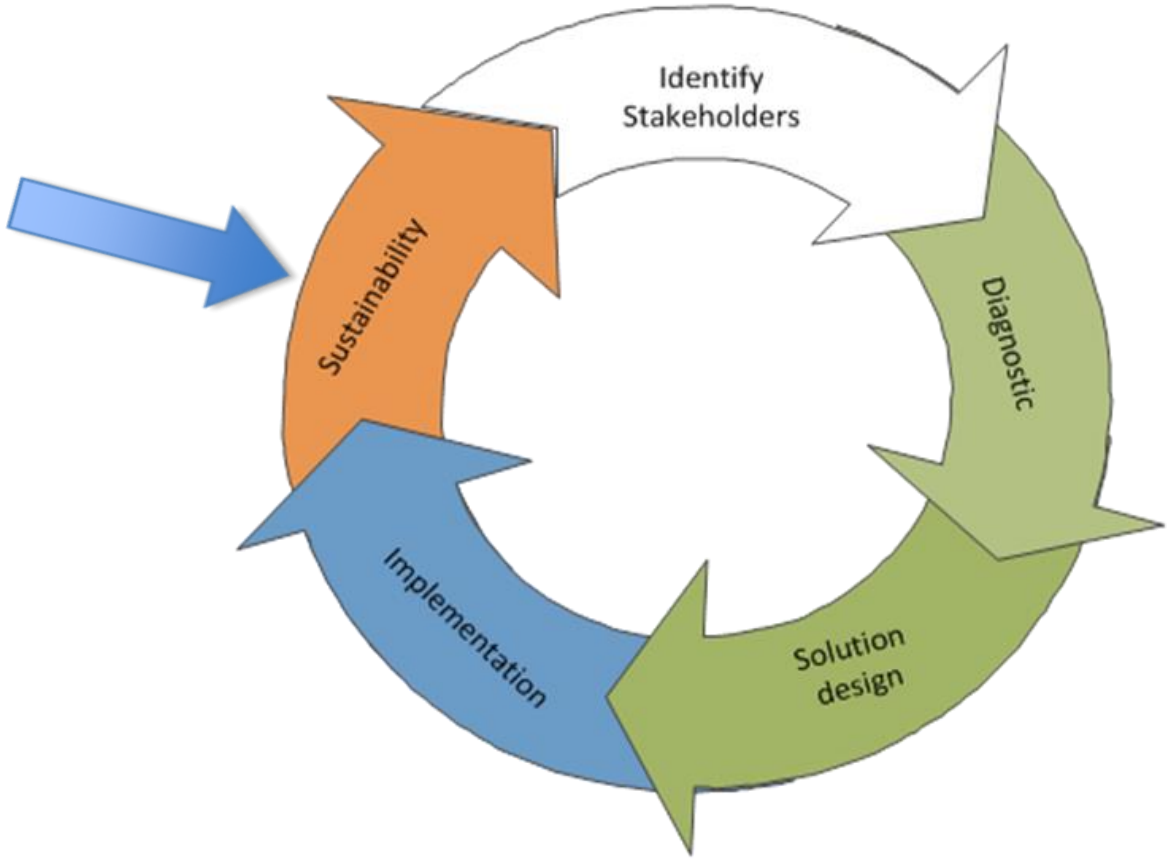
Burdett Transition QI Process – Sustainability



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

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Burdett Transition QI Process – Sustainability

Measuring the efficacy and standard of the Transition Service

Consider Key Performance Indicators review Quality Standard, including:

- 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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We Know….

One size does not fit all!

All organisations work in different ways. This work aims to support organisations to work in collaboration with the Young People and other professionals.

Goal - to provide preparation for adulthood for all young people and improve long term outcomes and life chances.

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Transition – Help!

- What would help you develop, deliver and sustain your Transition service?

Please go to slido.com

Enter code: 3534807

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South Thames Paediatric Network
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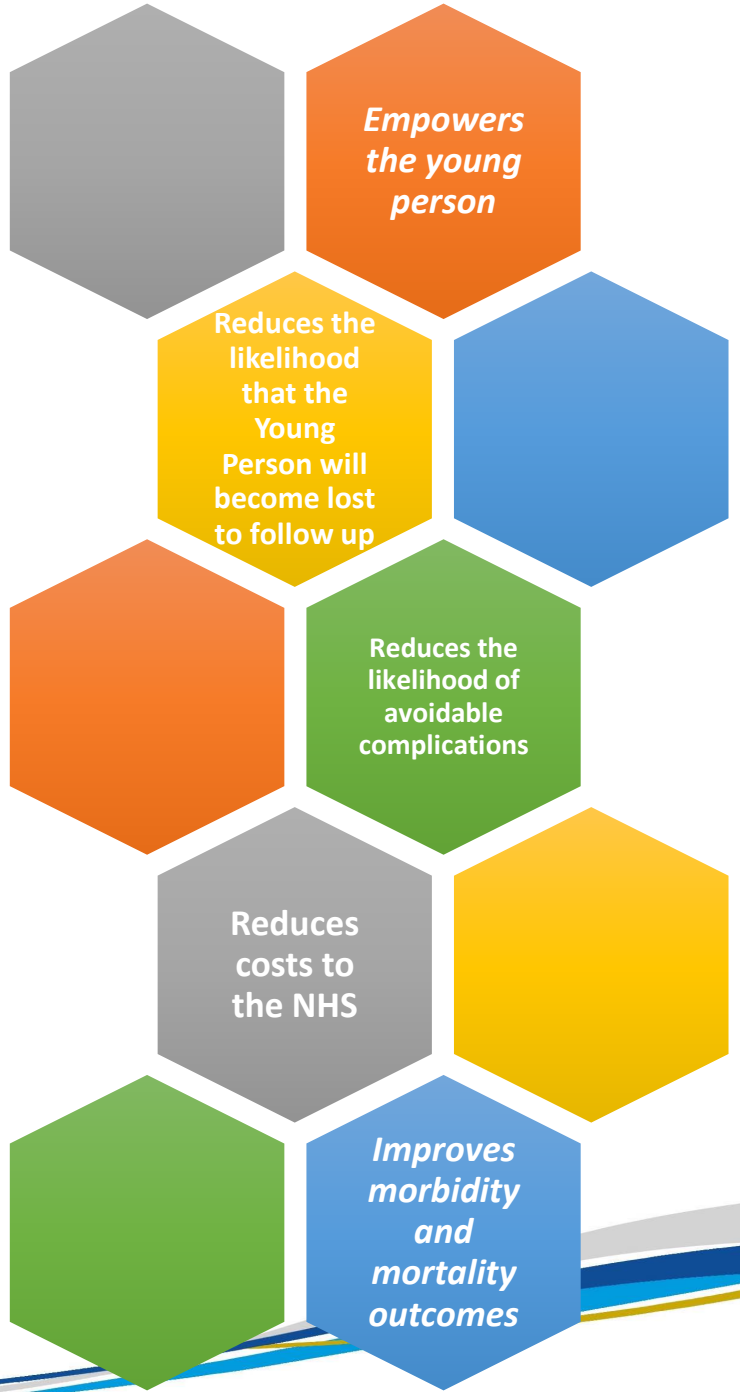
Transition

Effects & Benefits



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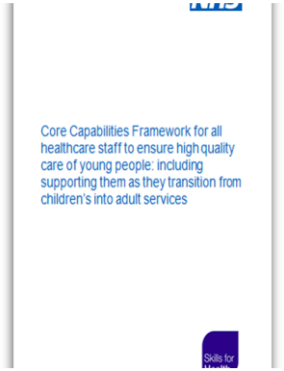
Session 2: January 2023

- Understanding Transition and building an effective and sustainable Transition Service.
- An overview of the key National Guidance and Frameworks informing the development of Transition Services.
- Practical demonstration of the Transition Project Plan.

Call to action = Commence ‘How to get started’ guidance



Key Documents

Project Plan

How to get Started

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Sessions 3-6: Delivered Monthly February to May 2023

- Subsequent sessions will cover 1 or 2 aspects of the Burdett Transition QI process.
- Sections to include practical examples throughout, including an overview of the Transition Tools available, Transition Lead Roles and the Lived experiences of young people
- Final session will include an overall summary, next steps and future planning as call to action.

	Session 3	Stakeholder Analysis Transition Toolkit 1 & 2
	Session 4	Diagnostic / Solution design Transition Toolkits 3 & 4
	Session 5	Implementation The Role of The Transition Lead
	Session 6	Sustainability Summary of Transition events and learning
	***Next steps and future planning - call to action.***	

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Next Steps

- Transition: Things to do to get started

  - A call to action

1. **Familiarise yourself with the key documents that outline best practice for Transition, including the NICE Guidelines (NG34), You're Welcome Criteria, and the CQC From the Pond to the sea.**
2. **Identify which professionals will need to be involved in providing transition care to patients in your service.**
3. **Start Data collection – How many Young People are there in your service who will need a Transition Plan?**

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Key Documents

NICE Guidance & Standard for transition NG43 QS 140 (2016)
Gold standard principles for transition, help to design transition process
National framework for transition (coming soon)
Principles for delivering and commissioning transition including minimum standard for care outlined
Capability framework (coming soon)
Assessment document for the skills, knowledge and behaviours staff require when caring for young people, including transition
National training package (coming soon)
Training for the care of young people and transition
You're Welcome 2017 & 2011
To be use to assess if healthcare services are young person friendly
Benchmarks for transition 2016
Assessing services against best practice for transition identifying areas of good and poor practice tool for process improvement
Northumbria Tool kit for transition
Recommendations for effective transition processes
Together for Short Lives Guide to Stepping up
A guide for transition of complex needs patients
tools for Young people and families as well as professionals

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Links

Transition

NICE Guidance for Transition 2016
https://www.nice.org.uk/guidance/ng43
NICE Standard for Transition 2016
https://www.nice.org.uk/guidance/qs140
SEND Code of Practice
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf
Northumbria Tool Kit for Transition 2018
https://www.northumbria.nhs.uk/quality-and-safety/clinical-trials/for-healthcare-professionals/#0fc61122

Young Person Friendly

Your Welcome criteria 2011
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216350/dh_127632.pdf

Complex needs

Together For Short Lives (TFSL) Guide to stepping up
https://www.togetherforshortlives.org.uk/resource/transition-adult-services-pathway/

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Thank You

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