# Improving Transition

|  |  |  |
| --- | --- | --- |
| 10:00 | **Registration**Tea and coffee on arrival. |  |
| **SESSION** **1** Chair: Simon Pleydell, Chair of the External Advisory Board to the Programme |
| 10:30 | Introduction. | Jim MackeyChief Executive, NHS Improvement |
| 10:40 | Background to transition and the implications of our research. | Allan Colver |
| 11:15 | What works in transitional care?What does economic analysis tell us? | Helen McConachieLuke Vale |
| 11:35 | Discussion and questions. |  |
| 11:50 | **Coffee and biscuits** |  |
| 12:10 | What is Developmentally Appropriate Healthcare?Lessons learnt and implications for commissioners. | Tim RapleyGreg Maniatopoulos |
| 12:30 | Discussion and questions. |  |
| 12:40 | What are the implications of the research findings for adults’ services? | Helena Gleeson, Royal College of Physicians |
| 12:50 | Discussion and questions. |  |
| **SESSION 2a**  |
| 13:00 | Breakout sessions. |  |
|  | A Launch of Toolkit to support the delivery of:‘Developmentally Appropriate Healthcare’There will be a short presentation, then opportunity to view the toolkit, then discussion about how it might be usedB Patient and public involvement in the Programmei) Young person's advisory group UP: one minute introduction on each of three posters, then viewingii) PPI lead: Reflections on PPIiii) Council for Disabled Children: Development of facilitator guidesC Indicators for TransitionTeresa Fenech from NHS England will lead discussions on possible indicators of transition. | Jeremy ParrJanet McDonaghGeorge ForsythJoseph McElderryAthena Winchester-ShoreGail Dovey-PearceCaroline BennettTeresa FenechNHS England |
| 13:35 | **Lunch** |  |
| **SESSION 2b** |
| 14:15 | Repeat of breakout sessions. |  |
| **SESSION 3** Chair: Ann Le Couteur |
| 14:50 | Keynote critique:What are the implications of the research findings for the NHS? | Jackie Cornish, National Clinical Director for Children, Young People and Transition to Adulthood |
| 15:00 | Discussion and questions. |  |
| 15:10 | Keynote critique:How do the research findings relate to international research in the field? | AnneLoes van Staa, Professor of Transitions in Care, Rotterdam University of Applied Sciences |
| 15:20 | Discussion and questions. |  |
| **Session 4** Panel discussion with the audience |
| 15:30 | Chair of Panel: Helena Gleeson | Members of panel: Debbie Reape, Jackie Cornish, AnneLoes van Staa, Allan Colver, Athena Winchester-Shore and Gail Dovey-Pearce |
| 15:55 | Concluding remarks. | Allan Colver |
| 16:00 | **Finish** |  |

**Conference on Transition of young people with long term conditions from child to adult services**

**Marlborough Theatre, Kings Fund, London**

**Thursday October 12, 2017**

# Purpose of the meeting

Dissemination of the findings and implications of the Transition Research Programme for Transition of young people with long term conditions from child to adult services.

# Disclaimer and thanks

This conference summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0610-10112). The views expressed are those of the presenters and not necessarily those of the NHS, the NIHR or the Department of Health

We acknowledge the support of the NIHR Clinical Research Network

We thank the sponsor, Northumbria Healthcare NHS Foundation Trust

The presentations are made on behalf of the Transition Collaborative Research Group

**The website of the Research Programme is**: <http://research.ncl.ac.uk/transition/>

**This pack can be down-loaded from our website – as can the PowerPoint presentations from the Research Team**

**Today’s talks are being video recorded and in due course will be available on our website**

# Key implications for the practice of commissioners, managers and clinicians

**1 Transitional care should be commissioned by commissioners of adult services as well as by commissioners of child services.**

We found that commissioners and providers regarded Transition as the responsibility of children’s services; this is inappropriate as Transition extends to approximately age 24.

**Where an adult service to which to transfer young people with a long term condition is not commissioned, commissioners should set out explicitly that the transfer arrangements will usually be to primary care, and require appropriate documentation and assistance to the young person to make their first appointment.**

**2 A framework to provide ‘Developmentally Appropriate Healthcare’ across NHS organisations should be commissioned, with the stipulation that this is owned at Chief Executive and Board level.**

‘Developmentally Appropriate Healthcare recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations.

In operational terms Developmentally Appropriate Healthcare focuses on the approach of healthcare professionals to and engagement with each young person and their carers, alongside the structure of the organisations in which care takes place.’

**3 NHS organisations should adopt a Trustwide approach to implementation of better transitional care. A Transition Steering Committee, chaired by a Trustwide Transition Coordinator, can facilitate this.**

We found that in many Trusts good practice led by enthusiasts rarely generalised to other specialties or to adult services. At sites we visited where there was a Transition Steering Committee, chaired by a Trustwide Transition Coordinator, this took advantage of the skills and enthusiasm of those already providing good practice; and assisted with training and consistent implementation in adult and child services and across specialties.

**4 Child clinicians should plan Transition procedures jointly with the relevant named adult clinicians and general practitioners.**

This is not just about the transfer of individual young people; it is also about joint planning of the services for transitional care; in other words the framework of Developmentally Appropriate Healthcare and the features of transitional care services the Research Programme found to be beneficial.

**5 Child and adult healthcare providers should explore with a young person how they approach Transition and personalise the clinical approach thereafter.**

We found there were four broad interaction styles that young people adopted when approaching their Transition: ‘laid back’, ‘anxious’, ‘wanting autonomy’, and ‘socially oriented’ (welcomed support from and frequent discussions with family, friends and all healthcare professionals).

**6 The features ‘Appropriate parent involvement’, ‘Promotion of young people’s confidence in managing their health condition (health self-efficacy)’ and ‘Meeting the adult team before transfer’ were associated with greater satisfaction with services, participation, subjective wellbeing and measures of disease control.**

Therefore, we advise consideration should be given to ensuring that a commissioning specification includes that these feature are delivered by NHS organisations.

**7 Maximal service uptake would be achieved by a service which encouraged parental involvement, ensured the same staff were seen at each clinic, emphasised the importance of good communication with young people, and encouraged young people to make decisions about their care.**

**Good value for money would be offered by a service which provided: ‘Parental involvement that suited both parent and young person’, and a ‘Protocol for promotion of young people’s confidence in managing their health condition’.**

# Developmentally Appropriate Healthcare - Definition

Developmentally Appropriate Healthcare (DAH) recognises the changing biopsychosocial developmental needs of young people, and the need to empower young people by embedding health education and health promotion in consultations.

In operational terms DAH focuses on the approach of healthcare professionals to and engagement with each young person, alongside the structure of the organisations in which care takes place.

One workshop at the conference launches the toolkit we have developed on this topic. The toolkit is available from: https://www.northumbria.nhs.uk/dahtoolkit

# New understanding of adolescent brain development

This intriguing area of new knowledge results from all the new techniques available to image the human brain, at rest and undertaking mental tasks. We now know that the anatomy of the brain changes massively between ages 11 and 24; some regions of the brain become more dominant for a time and are then restrained by the later maturation of other regions. Information processing speeds up and becomes more focused as connections between brain cells (grey matter) are pruned; and tracts (white matter) between regions of the brain transmit more efficiently as they enlarge and become better insulated.

On the surface of the brain, near the front, is the region (the pre-frontal cortex) responsible for more-or-less conscious control of short and long term planning, emotional regulation, decision making, impulse control and reflective thought. This is the last part of the brain to mature, not achieving this until age 24. Its relatively immature control at age 11 may be over-ridden by regions in the centre of the brain (limbic system and basal ganglia) which mature faster. These latter regions generate behaviours such as novelty seeking, risk taking and peer interaction which are reinforced by dopamine – a chemical transmitter in the brain which increases during adolescence. Much of the time, this potential imbalance between central stimulation and inhibition by the prefrontal cortex is kept in check but at times of excitement or stress and especially when with peers, inhibition may be overridden (so-called hot cognition).

Contrary to popular belief, the sex hormones (‘raging hormones’) are not responsible for these changes in the structure and function of the brain or the characteristic behaviours of adolescents. Of course, the sex hormones do determine the development of sexuality; but they are not responsible for the moodiness, excitability, increased reliance on peers, risk taking and the imaginative grasping of life which teenagers display.

Whilst many healthcare professionals seek to understand their adolescent patients and empathise with the challenges they face, some healthcare professionals feel out of their depth, may be upset by their interpretation of what an adolescent has said (or not said) and may even be irritated by adolescents. Understanding how different the adolescent’s brain is to their own may help child and adult healthcare professionals relate better to adolescents and thereby promote their health.

More information: Colver A, Longwell S. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. Archives of Disease in Childhood 2013:98(11):902-7.

# Lessons about involvement of young people in research

The length of our Research Programme really helped. The members of the young person’s advisory group (UP) could pace their engagement. Some avenues of work did not really work but in a five-year programme there was plenty of time to try other directions. Further, it took at least four meetings before the members of UP began to feel relaxed in each other’s presence. Elements that were important during those four meetings and subsequently were:

Code of conduct (ground rules)

Peer support workers

Practical help with travel to meetings (taxis etc.)

The members of UP grew in confidence. Whilst this was not the primary purpose of having a group, it is pleasing to know that all the effort UP members put in was also helpful to them.

# Academic publications

These are listed on and downloadable from the transition website <http://research.ncl.ac.uk/transition/>resources/papers

We have published:

A review article on adolescent brain development

The protocol for the longitudinal study

Analysis of baseline data in the longitudinal study

Young people’s approach to transition

Findings from interviews with commissioners

Two articles on Developmentally Appropriate Healthcare

An article on the properties of a mental health instrument

Seven further articles are submitted or are in preparation

# Final Report

This has been submitted to NIHR and in due course will be published in the NIHR Publications Library.

# Chairs and Speakers

Simon Pleydell, Chair of Humber Coast and Vale Sustainability and Transformation Plan

Jim Mackey, CEO, NHS Improvement

Allan Colver. Programme Lead. Professor of Community Child Health, Newcastle University

Helen McConachie. Co-applicant. Professor of Child Clinical Psychology, Newcastle University

Luke Vale, Co-applicant, The Health Foundation Professor of Health Economics, Newcastle University

Tim Rapley, Co-applicant, Senior Lecturer Medical Sociology, Newcastle University

Greg Maniatopoulos, Senior Research Associate, Medical Sociology, Newcastle University

Helena Gleeson. Advisor to Programme Board. Consultant Endocrinologist, University Hospital Birmingham NHS Foundation Trust and Royal College of Physicians

Jeremy Parr, Co-applicant, Senior Lecturer in Paediatric Neurodisability, Newcastle University

Janet McDonagh, Co-applicant, Consultant Adolescent Rheumatologist, University of Manchester

Representing UP group: George Forsyth, Joseph McElderry, Athena Winchester-Shore

Gail Dovey-Pearce, Co-applicant, Consultant Clinical Psychologist, Northumbria Healthcare NHS Foundation Trust

Caroline Bennett, Co-applicant, Deputy Director, Council for Disabled Children

Teresa Fenech, Director of Nursing and Quality Assurance, Specialised Commissioning, NHS England

Ann Le Couteur, Co-applicant, Professor Child and Adolescent Psychiatry, Newcastle University

Jackie Cornish, National Clinical Director for Children, Young People and Transition to Adulthood

Anneloes van Staa, Professor of Transitions in Care, Rotterdam University of Applied Sciences

Debbie Reape, Co-applicant, Deputy Director of Nursing, Northumbria Healthcare NHS Foundation Trust

# Delegates

Stephen Atkinson Policy Lead, Long Term Conditions and Primary Care, Department of Health, England

Michelle Baylis Chartered Society of Physiotherapy and Association of Paediatric Chartered Physiotherapists

Caroline Bennett Council for Disabled Children

Bryony Beresford Co-Director, Social Policy Research Unit, University of York

Patrick Butler Guardian

Sally Caldwell Diabetes UK

Lizzie Chambers Together for Short Lives

Anita Charlesworth Director of Research, The Health Foundation

Katherine Chartres Liaison Committee, Royal College of Psychiatry

Nicola Chater Consultant in Adult Rehabilitation, Northumberland Tyne and Wear NHS Trust

Allan Colver Professor of Community Child Health, Newcastle University and Northumbria Healthcare NHS Trust

Anne Colver Retired General Practitioner, Northumberland

Rachel Conner Research Programmes Branch, Department of Health, England

Jaqueline Cornish National Clinical Director for Children, Young People and Transition to Adulthood

Gail Dovey-Pearce Consultant Clinical Psychologist, Northumbria Healthcare NHS Trust

Helen Eke Exeter University

Harrison Evans Programme Manager, National Institute of Health Research

Louise Everett Policy Lead, Deputy Director Primary Care, Department of Health, England

Albert Farre Research Associate, Birmingham University

Teresa Fenech Director of Nursing and Quality Assurance, Specialised Commissioning, NHS England

George Forsyth Young Person, Northeast England

Stephen Garfield-Birbeck NIHR Evaluation, Trials and Studies Coordinating Centre

Helena Gleeson Consultant Physician, Royal College of Physicians

Victoria Gray Clinical Psychologist, North West Coast Collaboration for Leadership in Applied Health Research and Care

Anne Greenough Professor of Paediatrics, Royal College of Paediatrics and Child Health

Penny Greenwood Public Health England

Dougal Hargreaves Senior Clinical Research Fellow, University College, London

Emma Howard Consultant Physician, Royal College of Physicians

Margaret Johnson Consultant Physician and Academic Vice president, Royal College of Physicians

David Jones General Practitioner, Newcastle Gateshead Clinical Commissioning Group

Kevin Kelleher National Professional Advisor-Medical Specialities, Care Quality Commission

Terry Kemple General Practitioner, Royal College of General Practice

Dorian Kennedy Department of Health, England

Peter Kinderman Professor of Clinical Psychology, British Psychological Society

Ann Le Couteur Professor of Child and Adolescent Mental Health, Newcastle University

Beatrice Liddell University College, London

Stewart Long Director of Nations and Services, Arthritis Care and Arthritis Research UK

Jim Mackey Chief Executive, NHS Improvement, NHS England

Greg Maniatopoulos Senior Research Associate, Medical Sociology, Newcastle University

Michael March Consultant Paediatrician, Regional Director London, Specialty Commissioning, NHS England

Helen McConachie Professor of Child Clinical Psychology, Newcastle University

Janet McDonagh Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology, University of Manchester

Joseph McElderry Young Person, Northeast England

Mel Meek Consultant Nurse in Child and Adolescent Mental Health, Avon and Wiltshire Mental Health Partnership NHS Trust

Hannah Merrick Research Assistant, Newcastle University

Alison Mulvenna Administrative Support, Newcastle University

Alison Murray Parent, North Tyneside

Arvind Nagra Consultant Paediatric Nephrologist, University Hospital Southampton NHS Trust

Jeremy Parr Senior Lecturer, Paediatric Neurodisability, Newcastle University and Newcastle upon Tyne Hospitals Trust

Matthew Peak Director of Research, North West Coast Collaboration for Leadership in Applied Health Research and Care

Simon Pleydell Chief Executive, Whittington Health NHS Trust

Caroline Potts R&D Manager, Northumbria Healthcare NHS Trust

Carol Povey National Autistic Society

Sue Protheroe Chair of NHS England Clinical Reference Group Paediatric Medicine

Suzannah Pye Policy Analyst, The Health Foundation

Tim Rapley Senior Lecturer, Medical Sociology, Newcastle University

Debbie Reape Acting Director of Nursing, Northumbria Healthcare NHS Trust

Diane Reeves General Practitioner and Chief Accountable Officer, Birmingham South Central CCG

Emma Rigby Association of Young People’s Health

Swaran Singh Professor of Mental Health and Wellbeing, University of Warwick

Kathy Smethurst Mental Health Policy, Department of Health, England

Edward Smith Autistica

Fiona Smith Royal College of Nursing

Harriet Stewart Consultant Child and Adolescent Psychiatrist, Royal College of Psychiatry

Jaqueline Story Administrative support, Northumbria Healthcare NHS Trust

David Strudely Chair, Transition Taskforce, Together for Short Lives

Rachel Tattersall Consultant Physician, Royal College of Physicians

Nandu Thalange Retired Consultant Paediatrician

Luke Vale Professor of Health Economics, Newcastle University

AnneLoes van Staa Professor of Transitions in Care, Rotterdam University of Applied Sciences

Russel Viner Professor of Adolescent Health, University College, London

Elizabeth Ward North Hampshire CCG

Gabriel Whitlingum Consultant Paediatrician, British Academy of Childhood Disability

Peter Wilson Clinical Chair, Women and Children Programme of Care Board, Specialised Commissioning, NHS England

Athena Winchester-Shore Young Person, Northeast England

Paul Wright British Association of Community Child Health

Rohana Wright Consultant Physician, Royal College of Physicians

# We thank the following people who have contributed to the Research Programme

# External Advisory Board

Simon Pleydell, Chair, CEO Whittington Hospital

Allan Colver, Chief investigator, Newcastle University

Alison Murray, Parent

Harrison Evans, NIHR

George Forsyth, Young Person

Joseph McElderry, Young Person

Athena Winchester-Shore, Young Person

Marij Roebroeck, Movement science, Erasmus University Medical Centre

AnneLoes van Staa, Transition studies, Rotterdam University of Applied Sciences

Lizzie Chambers, Together for Short Lives

Chris Price, Sponsor, Northumbria Healthcare NHS Foundation Trust

Carl May, University of Southampton

Scott Wilkes, General Practice, University of Sunderland

# Programme’s Management Board

**The co-applicants for the Programme Grant**

Chief Investigator. Allan Colver, Community Paediatrician, Newcastle University and Northumbria Healthcare NHS Foundation Trust

Debbie Reape, Deputy Director of Nursing, Northumbria Healthcare NHS Foundation Trust

Council for Disabled Children. Amanda Allard, Caroline Bennett

Janet McDonagh, Adolescent Rheumatologist, University of Manchester

Ann Le Couteur, Child and Adolescent Psychiatry, Newcastle University and Northumberland Tyne and Wear Trust

Helen McConachie, Child Clinical Psychology, Institute of Health and Society, Newcastle University

Luke Vale, Health Economics, Institute of Health and Society, Newcastle University

Tim Rapley, Medical Sociology, Institute of Health and Society, Newcastle University

Mark Pearce, Epidemiology, Institute of Health and Society, Newcastle University

Jeremy Parr, Neurodevelopmental Paediatrics, Institute of Neuroscience, Newcastle University and Newcastle upon Tyne Hospitals Trust

Gail Dovey-Pearce, Consultant Clinical Psychologist, Northumbria Healthcare NHS Foundation Trust

**Lead for commissioning**

Greg Maniatopoulos, Medical sociology, Institute of Health and Society, Newcastle University

**Advisors**

Helena Gleeson, Adult Endocrinology, University Hospital Birmingham NHS Foundation Trust

Nichola Chater, Adult rehabilitation, Northumberland Tyne and Wear Trust

Caroline Potts. Representing Debbie Reape, Northumbria Healthcare NHS Foundation Trust

# Collaborators

Stuart Bennett, Northumbria Healthcare NHS Foundation Trust

Stephen Bruce, Northumbria Healthcare NHS Foundation Trust

Belinda Bateman, Northumbria Healthcare NHS Foundation Trust

Amanda Billson, Royal United Hospital Bath Trust

Tim Cheetham, Newcastle Hospitals NHS Foundation Trust

Zilla Huma, Heatherwood and Wexham Park Trust –until 2014

Fiona Regan, Frimley Health NHS Foundation Trust - from 2014

Cara Maiden, North Bristol Trust – until 2013

Dianna Howlett, North Bristol Trust -2013-2015

Helen Mason, Glasgow Caledonian University

Jenny Milne, Tees, Esk and Wear Valleys Trust

Jackie Parkes, Queens University, Belfast – until 2014

Mark Linden and Maria Lohan, Queens University, Belfast – from 2014

Melanie Meek, Avon and Wiltshire Mental Health Trust

Nandu Thalange, Norfolk and Norwich University Hospitals Trust

Shona Haining, Northeast Commissioning Support Group

# Research assistants

Tracy Scott Kate Hardenberg

Louise Ting Shaunak Despandi

Guiomar Garcia Jalon Holly Roper

Hannah Merrick Rose Watson

Michaela Fay Jenni Hislop

Catherine Sheppard Sarah Balne

Louise Foster Julija Stoniute

Louisa Fear Kay Mann

Kam Ameen Ali Hazel Windmill

Charlotte George Victoria Wood

Albert Farr

# Other assistants

Participation workers: Dan Notley, Amy Jones

Peer-support workers: Sophie Fairgrieve, Sophie Walker, Monica Parker, Molly Pledger

Student helpers: Sarah Longwell, Rachel Pearse, Vito Puyat, Folasade Solanke

Secretarial, financial and administrative staff: Sarah Nolan, Alison Mulvenna, Jaqueline Story, Norman Marillier