NHS
Greater Manchester
and Eastern Cheshire
Strategic Clinical Networks

Event Report

Greater Manchester Children’s and Young People’s Network Meeting

Freefall to Parachute: Enabling Safe Transitions for Adolescents and Young Adults with Long-Term Conditions

Event Date: Friday 26th September 2025
Venue: British Muslim Heritage Centre, Manchester

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1. Introduction and purpose

This Children and Young People (CYP) Network meeting considered the evidence base for supporting adolescents and young adults (AYA) with long-term conditions through a transition process that enables safe transfer from paediatric to adult healthcare services. A range of stakeholders including but not limited to young people, parents and carers, NHS provider trusts, community and voluntary sector, local authority, NHS Commissioning bodies (Greater Manchester Integrated Care Board and NHS England considered policy and practice, exploring the opportunities and challenges of working with adolescents and young adults and avoiding disengagement with healthcare services after transfer. Examples of best practice where transition and transfer are done well were shared along with data that supports a case for change in the way we support AYA through their health and care journeys.

1.1. Aims of the event

The event considered transition for AYA with long-term conditions and sought to identify common themes and recommendations that could apply generically to healthcare transition, regardless of which setting or organisation the AYA accessed their health services through, promoting transitions and moving away from transfers of care. It aimed to:

- Influence the way that adolescent and young adult healthcare is delivered in Greater Manchester, with a particular focus on the transition process from paediatric to adult services.
- Gain commitment from stakeholders to take forward key actions that will contribute to a better experience of healthcare transition and transfer for adolescent and young adults.

1.2. Objectives

- Identify opportunities, challenges and barriers and develop solutions to support safe transition within the context of the three shifts identified in the NHS Ten-year Plan:
    - Sickness to prevention
    - Analogue to digital
    - Hospital to community
- Share examples of best practice and case studies where adolescents and young adults have successfully transferred over to adult services.
- Understand what successful transfer looks like.
- Bringing together key stakeholders in paediatric and adult services including commissioners, clinicians, finance, primary care, mental health, GMCA, education, youth workers, parents/carers, adolescents and young adults.
- Identify learning and generic principles from transition in long-term conditions services that can be applied to other settings.
- Identify areas for further development and the focus of follow-up workshop sessions.

1.3. Contributors and acknowledgements

Thanks to the contributions of the following people without whom this event would not have been the success that it was:

To Dr. Easwari Kothandaraman for clinical leadership and expert chairpersonship throughout the event.

To our young people, Sameer, Rosie, Ayyub and Grace for setting the scene from their perspective, and to Nic Rigby, Rachael Pearson and Molly Bradley from RMCH for their support prior to and during the event.

To colleagues Dr. Jim Ritchie and Dr. Hood Thabit for reminding us of the importance of good transition care for adolescents and young adults with healthcare needs.

To Louise Rule for providing the Greater Manchester context of transition health care, and to colleagues from the Stockport NHS Foundation Trust, Chris Milton-Bolland and Kyla Howard for showing us the positive impact that dedicated transition care can have on young people's health and broader outcomes.

To the GMEC SCN clinical advisors, Dr. Chris Cooper, Dr. Claire Murray, Alison Senior and Julie Flaherty for their contributions on the day, and their ongoing clinical leadership for the Long-term Conditions programme, with mentions to Debbie Garner and Dr. Amy Wilson for their clinical leadership around CYP epilepsy.

To the GMEC SCN team- Afia Ali, Nida Fatima, Frances Carbery, Lianne Amato and for their organisational skills and facilitating the technology that enabled this event to take place.

2. Welcome and introductions

Dr. Easwari Kothandaraman, GMEC SCN Children and Young People's Clinical Lead and Consultant Paediatrician at the Royal Manchester Children's Hospital introduced herself and welcomed all to the event. An overview of the programme and the aims of the day were provided, and attendees were asked to consider: ***What does healthcare transition mean to you?*** Answers were submitted through Mentimeter.

- Next step in growth and development.
- Vision - would be the journey that takes place from children's services to adult services. My experiences would say it's how disconnected and underfunded the journey is for CYP into adult services.
- Successful engagement in health and confidence to manage into adulthood
- Moving from one stage to another
- The process where Children and young people move in a (hopefully) streamlined way to adult services.
- It means offering a continuous treatment with nobody getting lost in the system.
- Seamless care with joined up collaboration

3. Transition in context

3.1. Adolescent and Young Adults (AYA) video: what young people are saying.

The Manchester University Hospitals NHS Foundation Trust (MFT) youth worker team, based at the Royal Manchester Children's Hospital (RMCH) had spoken to AYA that they work with about their views on transition. They produced a video which was presented at the event, but not for wider sharing. Reflecting upon the video, Dr. Kothandaraman commented these were powerful words, with the AYA involved talking about feeling scared, describing doctors as the bosses and how different the adult hospital wards were compared to children's wards. All were asked to consider the AYA voice throughout the afternoon.

3.2. How far have we come?

Dr. Kothandaraman described some of the previous work that had been done in Greater Manchester to improve transition care in the context of the NICE Guideline: Transition from children's to adults' services for young people using health or social care services (NICE, 2016). Pilot projects in a number of areas had been tested with provider Trusts implementing transition programmes such as *Ready, Steady, Go* (Arvind, Davis, McGinnity & Salmon, 2016), Alder Hey's 10 Steps Programme (Aizelwood, Brooks, Kaehne & Rogers, 2017) and Multidisciplinary team (MDT) approaches to transition care.

Currently there are national pilots with diabetes teams underway, one of which is in Stockport, and a national youth worker pilot which is being tested in Oldham and Rochdale with AYA with epilepsy. The epilepsy youth worker sits within a larger team within MFT which works across a broad range of conditions. In 2024 a *Getting It Right First Time* (GIRFT) review of diabetes care for 16–25-year-olds took place in Greater Manchester (GM) and recommendations were made for improvements which are being addressed through the GM CYP Diabetes Group and GM Diabetes Oversight Group. A GM Diabetes Transition Strategy was developed jointly between paediatric and adult stakeholders in the same year. There is also a GM Epilepsy Transition Working Group which has produced standardised documentation to support smooth transfer of care between children's and adult services.

Despite much progress having been made over the past ten years, there remains variation in care and outcomes across Greater Manchester whereby not all areas have transition provision or young adult care and may offer 'hand-over' clinics or nothing at all. The challenges of care provision for this unique patient group were highlighted throughout the afternoon in patient stories, shared clinician experiences and the question-and-answer sessions.

3.3. Rosie's story

"I'm a student nurse due to qualify in January. I am passionate about advocating for young people because I have first-hand experience of being in and out of hospitals as well as clinical experience. This allows me to see areas for change from both

Rosie described her experience of moving between children's and adult healthcare services stating that the changes happen quickly and describing how it feels to be a young adult accessing healthcare services in the broader context of other aspects of a young adult's life.

> Hello everyone,
>
> Today, I want to talk about something that many young people go through, but often without the preparation or support they really need - the transition from children's health services to adult health services.
>
> This is a major step, and while it's often treated like just a change of hospital or a change of doctor, it's actually a lot more than that. It's emotional, it's personal, and it happens during a time when life is already full of other pressures and changes.

Differences

Let's begin with the differences between the two systems.

When you're under children's services, things feel more joined up. You're often seen in one hospital, with a team you've known for years. Appointments are made for you, your parents or carers are often involved, and there's usually a gentler, more nurturing approach. There's a sense of familiarity and support.

But when you move to adult services, that changes quickly. You're expected to be independent - to book your own appointments, manage your own medications, advocate for yourself, and attend alone. Communication is now directed to you, not your parents, and you're suddenly responsible for managing everything, sometimes with little to no help.

And it's not just one team anymore. You might go from being treated in one hospital to being under multiple different specialist hospitals, each with their own admin teams, locations, and procedures. That makes managing care far more complex.

Transitioning to adult A&E

Moving from children’s to adult A&E is a massive and often frightening shift. In children’s, you’re usually surrounded by babies, young children, and a calm, more supportive environment. Suddenly, in adult A&E, you're exposed to things that can be really scary—the language you hear, the behaviour you witness, and even the people around you. You might see individuals under the influence of drugs or alcohol, or even patients brought in under police escort. When you're already in the middle of a health crisis, being thrown into that kind of environment is overwhelming. On top of that, you're in an unfamiliar space, and the dynamic flips—you go from being one of the oldest in the room to the youngest by far. That change alone can make you feel small, vulnerable, and completely out of place. We need to recognise that this transition isn’t just clinical—it’s emotional and psychological too.

Life Issues and Change at 18: Life Stresses

Outside of Healthcare

Now imagine that happening at 18 - a time when most people are already juggling major life changes.

You might be starting university, a job, or an apprenticeship. Maybe you're moving out of home for the first time. You're figuring out how to manage money, new relationships, coursework, and your identity. Life is shifting - rapidly.

And then, on top of that, your entire healthcare world changes. The safety net you've known your whole life is suddenly gone, and you're expected to manage hospital letters, book and attend multiple appointments, possibly travel to new cities for specialist care, and deal with all of this alone - often for the first time.

If you've moved away for university, this becomes even more difficult. You may not have someone to come with you. You're meeting new doctors in unfamiliar hospitals, explaining your history all over again, and trying to stay on top of your care while juggling everything else in life. It can feel overwhelming.

Benefits and What Could Have Helped the Transition Go Smoother

Now, it's important to say - adult services do have benefits. There's more autonomy, more say in your treatment, and a chance to take control of your own health journey. That can be empowering.

But to get to that point, the transition needs to be smoother. Here are some things that could really help:

- Better preparation: Conversations about transition should start much earlier - ideally around age 14 or 15 - so that it feels like a gradual process rather than a sudden cliff edge.
- Learning to book appointments early: Teaching young people how to book their own appointments while they're still in children's services, with support from staff and parents, would help build confidence and reduce anxiety later on.
- Managing multiple hospitals: In adult care, you may no longer have one team under one roof. Instead, you're sent to several specialist hospitals. That means multiple sets of appointments, admin systems, and letters. It's hard to juggle, and it's something that young people need to be supported through - not just expected to handle on their own.
- Mental health support: One of the hardest parts of transition is leaving a team you've built a strong relationship with - people who know you, who you trust, and who've supported you for years. Suddenly, you're meeting brand new teams of doctors, nurses, and specialists, often across different hospitals. That loss of connection and familiarity can have a real emotional impact, and we need better mental health support during this time.
- Admin overload: Once you're in adult care, letters come directly to you, appointments are your responsibility, and you're expected to understand how to navigate all of it. That's a lot to manage - especially when paired with big life changes like moving to university or starting work. Help with organising this information, and systems that make it easier, would go a long way.
- Setting clear, personalised adjustments: In children's services, it's normal for parents to be involved, to stay on the ward, or to come into appointments. In adult services, this often stops suddenly, without discussion. It would help massively if there were clear protocols allowing patients to set personal reasonable adjustments like having a parent attend appointments, longer consultation times, or consistency with certain staff. These should be discussed before the transition so that there are no surprises - especially for the most vulnerable.
- Introducing adult A&E: For those who regularly use emergency services, it would be really helpful to have an introduction to how adult A&E works. The system is different - from triage to treatment. Even a short tour, information session, or

leaflet could help make that transition feel less intimidating if and when it's needed in a crisis.

- Joint appointments: There should be an overlap where both children's and adult services meet together with the patient. This allows for a smoother handover, shared understanding, and continuity in care. It may also mean not having to explain your history all I’ve regain.
- Transition coordinators or champions: Having a named person to guide you through the process, answer questions, and help you navigate adult services could make a huge difference. Someone to ensure you don't fall through the cracks.
- Youth-friendly adult services: Adult services should be flexible and accessible to young people—offering appointment times that fit around college, uni, and work, and ensuring staff are trained to understand the unique challenges that 16–25-year-olds face. Transitioning into adult services can be overwhelming, especially when you're still finding your voice in complex systems. Sometimes, when you ask if a parent or trusted adult can come with you to support or help explain things, you're completely dismissed—and instead of talking to you, professionals start talking about you, like you’re not even in the room. It’s frustrating and isolating. Some doctors get it and work with you. Others judge you just for needing that support. That needs to change. Services should empower young people, not silence them. This can be done by ensuring staff are trained to understand the unique challenges that 16–25-year-olds face.

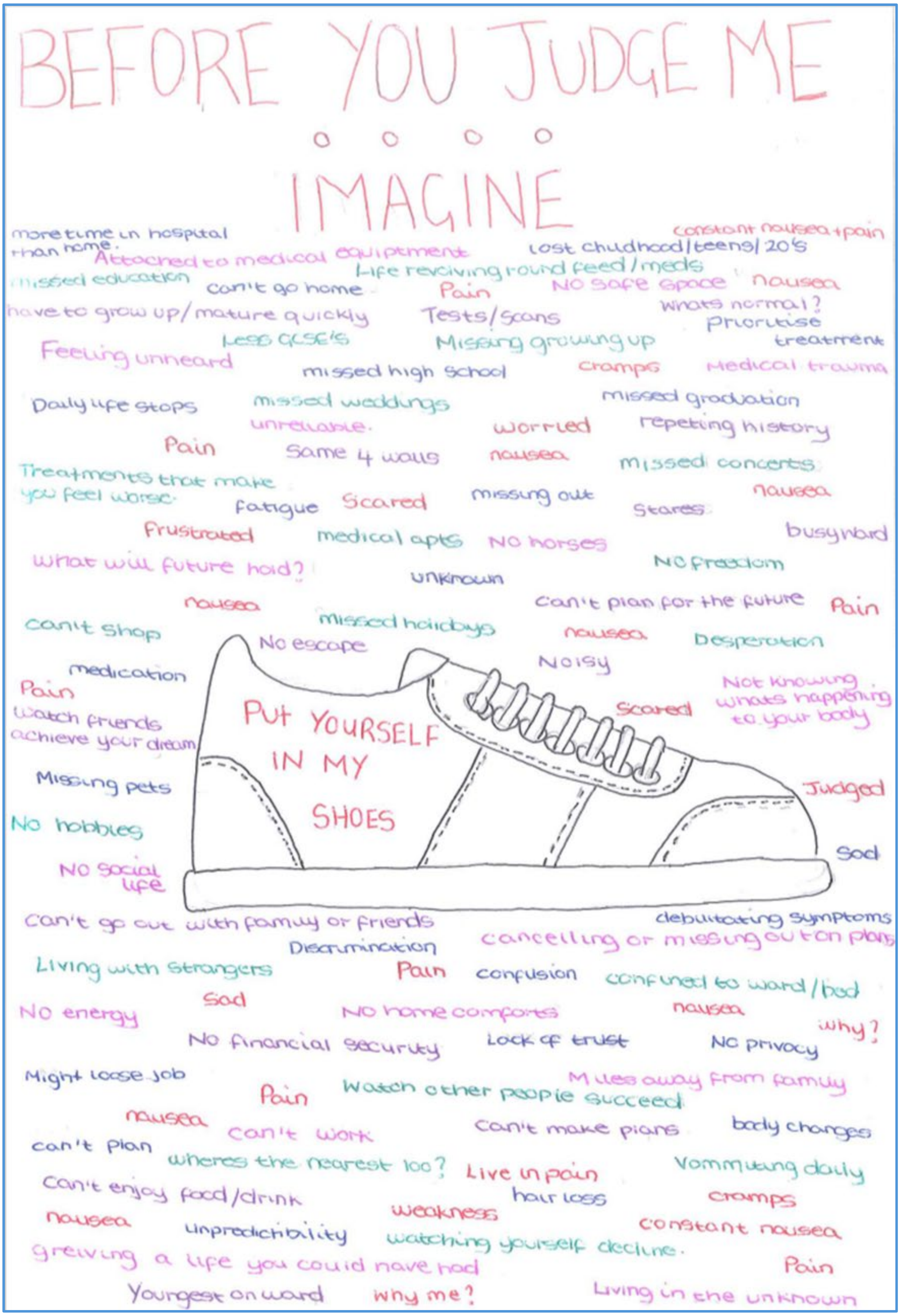
The move from children's to adult healthcare is more than just a change in hospital or doctors - it's a personal, emotional, and practical shift that happens at a time in life when everything else is changing too.

With better preparation, more emotional support, and systems that are built around the needs of young people, this transition can be made smoother, safer, and more empowering.

We don't expect 18-year-olds to suddenly know how to run their own lives in every other area, so we shouldn't expect them to instantly manage complex healthcare alone either.

With the right support, young people can thrive in adult services - but they shouldn't have to get there by struggling through it on their own.

Dr. Kothandaraman thanked Rosie for sharing her insights stating that some of these things should not be hard to achieve, asking all to hold this in mind through the afternoon. ”


BEFORE YOU JUDGE ME
o o o o
IMAGINE
more time in hospital than home.
Attached to medical equiptment
lost childhood/teens/20's
constant nausea + pain
missed education
can't go home
Life revolving round feed/meds
Pain
No safe space
nausea
have to grow up/mature quickly
Tests/Scans
whats normal?
Prioritise
Less GCSE's
Missing growing up
treatment
Feeling unheard
missed high school
cramps
Medical trauma
Daily life stops
missed weddings
missed graduation
unreliable.
worried
repeting history
Pain
Same 4 walls
nausea
missed concerts
Treatments that make you feel worse.
fatigue
Scared
missing out
Stares
nausea
Frustrated
medical apts
No horses
busy ward
What will future hold?
unknown
No freedom
nausea
Can't plan for the future
Pain
can't shop
missed holidays
nausea
Desperation
No escape
Noisy
medication
Pain
Watch friends achieve your dream
Put YOURSELF IN MY SHOES
Scared
Not knowing whats happening to your body
Missing pets
Judged
No hobbies
Sad
No social life
Can't go out with family or friends
debilitating symptoms
Discrimination
cancelling or missing out on plans
Living with strangers
Pain
confusion
confined to ward/bed
No energy
Sad
No home comforts
nausea
why?
No financial security
Lack of trust
No privacy
Might loose job
Miles away from family
Pain
Watch other people succeed
nausea
can't work
can't make plans
body changes
can't plan
wheres the nearest loo?
Live in pain
Vommiting daily
Can't enjoy food/drink
hair loss
cramps
weakness
nausea
unpredictibility
watching yourself decline.
constant nausea
greiving a life you could have had
Pain
Youngest on ward
why me?
Living in the unknown

3.4. Transitions through the lens of the Children & Young People Greater Manchester Joint Forward Plan | Louise Rule, Associate Programme Director for Transformation, NHS Greater Manchester Integrated Care

Louise provided a strategic overview of where healthcare transition sits within the Integrated Care Board (ICB) strategies and plans. Describing the Joint Forward Plan (JFP) for Greater Manchester, Louise remarked that the plan had been developed with the ten local areas in Greater Manchester and includes education and social care deliverables. In Greater Manchester, a separate integrated Children and Young People's Joint Forward Delivery Plan was developed with a vision to deliver an integrated approach to improving outcomes for Children and Young People and to tackle inequalities, putting the needs and experiences of CYP and their families at the heart.

Transition is mentioned within the plan which states that "children will receive developmentally appropriate care as they transition from child to adult long-term condition services." Additionally, an NHS GM SEND (Special Educational Needs and Disability) strategic priority is to develop a *Preparation for Adulthood Framework*.

Louise commented that there is a strong focus on Integrated Care Boards through strategic planning to embed transition planning in Joint Forward Plans and Integrated Care Partnership strategies, to consider population health data for CYP up to 25 years of age, and to develop localised Multidisciplinary team (MDT) models that reflect communities and workforce availability.

Furthermore, services should be jointly commissioned and designed with local authorities, and mental health, SEND and Long-term conditions services should be included in commissioning priorities, with acknowledgement that there is work to be done in this area in Greater Manchester. Louise also noted that workforce development was required to be able to deliver on transition outcomes.

Reflecting on CYP and family voice work that had been conducted across Greater Manchester, Louise commented that observations and issues associated with transition resonated with Rosie's words.

CYP voice in Greater Manchester is further amplified through the new Youth Shadow Board which operates in tandem to the ICB Systems Board, with the Lundy Model of participation framework providing a means for measuring impact of this Shadow Board.

Louise summarised by acknowledging the excellent work that is already happening, and the need to do more with healthcare transitions, stating that whilst children's services are inspected by the Care Quality Commission, adult services are not, and there are opportunities for improvement.

3.5. Young Adult Renal Clinic – the value of transition | Dr. Jim Ritchie, Deputy Chief Medical Officer, NHS Greater Manchester Integrated Care, Consultant Renal Physician, Salford

Dr. Ritchie shared his experiences of developing a young adult renal clinic, providing the rationale for the service and impact that was demonstrated. He began by talking about how kidney disease may manifest in children, including the impact on neurological development which influences behaviour.

Highlighting medical data that illustrated concordance challenges for patients who had received renal transplants, adversely impacting their transplant function, Dr. Ritchie noted that whilst graft survival in adolescents is excellent at 1-year, after 5-6 years (i.e. when moving between children's and adults' services) compared to other paediatric groups, survival rates are significantly reduced, making the case for good transition services.

Dr. Ritchie went on to describe socio-emotional development in adolescents that influenced compliance to treatments, whereby the adolescent's approach to their condition may be that they don't want to be seen as ill and are beginning to develop their self-identity. The needs of parents were also highlighted here, in particular for those with learning needs the transition support may be for the parent and not the young adult.

Other factors included education and examinations, body image issues, relationships and fertility and rebellion against parents, which may be more about their assertion of independence rather than intentional rebellion. This assertion of independence often may result in a period of reduced concordance with treatment and poor health associated with the disease.

Patient experiences and views were gathered through a focus group which resonated with those of other long-term conditions patients whereby they wanted to be considered as a person first and foremost, and not a disease/ condition. They also wanted support with other issues such as mental health and wellbeing, careers and finances, and they wanted to have access to peer support including through social media.

The service provision was developed as one of relationship-centred care, with involvement of a range of clinicians including psychologist, dietetic, nurse and urologist, with a key element of success being ongoing patient involvement. It adopted structured approaches to care including 'Ask 3 Questions', 'Ready Steady Go' and psychology screening tools, which nurse specialists supported with. A young adult renal network (YARN) was implemented, and peer mentors were introduced across a range of disease areas, alongside 'meet and greet' activities, including a Wayfinder video, tours etc. to support the introduction to adult care. Trust training and induction ensured staff were aware of the approach to young adult care.

Dr. Ritchie concluded by describing the impact the service had had on some of the young adults involved with positive outcomes including access to education, training, employment, and compliance with the treatment regime. Clinical outcomes over 10 years of the clinic running showed a reduction in the number of Young Adult patients who progressed to end stage kidney disease.

Dr. Ritchie noted that whilst the service had clearly demonstrated impact, there were challenges with service funding for a nurse, youth worker, clinical health psychology and peer mentors which were key to service provision. Additional challenges included the cohort size and management, sustainability of the YARN and the geographical footprint of the service which could make travelling difficult for some.

Dr. Ritchie concluded but posing questions about transition provision asking:

- How do we collect better data and share analyses?
- How do we offer consistent services for young people?
- How do we sustain patient-led services that are more accessible, with consideration for what remote care may involve.

3.6. Variation in Care & Outcomes in Young Adults with Diabetes: How disparities during adolescence and early adulthood shape long-term risk | Dr. Hood Thabit, Consultant Diabetologist Manchester Royal Infirmary, Senior Lecturer University of Manchester, Diabetes Transition Clinical Lead, GM Diabetes Network

Dr. Thabit stated that diabetes transition care has been around for more than 20 years, however there is still disparity in how this care is provided with literature identifying fragmented paediatric and adult services at the point of transfer, inequalities in access to and lack of support for technology use, and psychosocial challenges for this phase of care. He noted an estimation of 50-60% of young adults are lost to follow up (LTFU) after transferring to adult care, and of those who remain in services, only around 30% receive the recommended NICE care processes. There is around a 2.5-fold deterioration in HbA1c between the last paediatric appointment and the first adult appointment. This is a clinical marker for diabetes. HbA1c peaks at approximately 9.2% at aged 19 years, whereas ideally it should be around 6.5% or below. This can have a legacy effect causing health problems in later life. People from ethnic minority groups and more deprived areas are adversely affected, having higher HbA1c levels, and poorer access to technology that helps to manage this. There has been an increase in prevalence of Type 2 Diabetes in younger people below 30 years, and similar outcomes have been seen for these population groups compared to those with Type 1 Diabetes.

High risk behaviours such as insulin omission and alcohol intake lead to poor clinical outcomes for young adults during the transition period resulting in higher rates of attendance at emergency departments and an increased likelihood of admission to hospital. Dr. Thabit stated that it is important for adult A&E/ Emergency Departments to consider transition care provision.

Dr. Thabit described the longer-term impact of complications with diabetes during adolescence and young adulthood, noting that many adolescents aged 12-19 years with diabetes also show risk factors for cardiovascular disease (CVD), and 50-70% of these have signs of atherosclerosis (hardening of the arteries) by the age of 45 years. For those with early onset of type 2 diabetes, unplanned or no transfer of care results in a 4.4 x increased risk of poor HbA1c, with greater obesity rates and risk of CVD.

Noted was the work done in Greater Manchester that has begun to address transition provision in diabetes services, including the development of the Greater Manchester Diabetes Transition Strategy which was produced in conjunction with young adults, and paediatric and adult diabetes clinicians. Dr. Thabit emphasised the importance of young people’s voice and lived experience in strategy development, and the relevance to the three shifts in care described in NHS England’s 10 Year Plan.

Dr. Thabit concluded with a call to action on the following points:

- **Clinical teams**: need to have transition and transfer process in place, reporting on outcomes (GM Diabetes Transition Strategy).
  - Define what successful transfer looks like from the perspectives of young adults, carers, and professionals.
  - Identify challenges and barriers to safe transition and co-develop solutions within the three shifts of the NHS Ten-Year Plan:
    - Sickness → Prevention
    - Analogue → Digital
    - Hospital → Community
- **Everyone**: ensure continuity and proactive care for young people

    - Stakeholders across paediatric and adult services, including commissioners, finance, primary care, mental health, education, youth workers, parents/carers, adolescents, and young adults.
- **Funders and researchers**: Fill evidence gaps, agree on areas for further development.
    - Share examples of good practice and case studies where adolescents and young adults have successfully transferred to adult services.
    - Define what successful transfer looks like from the perspectives of young adults, carers, and professionals.
    - Bring together key stakeholders across paediatric and adult services, including commissioners, clinicians, finance, primary care, mental health, GMCA, education, youth workers, parents/carers, adolescents, and young adults.
    - Identify transferable learning and principles from transition in long-term condition services that can be applied in other settings.
    - Agree on areas for further development and set the focus for follow-up workshop sessions.

3.7. Panel Questions

The speakers answered questions posed by attendees:

Q. How do we sustain services such as the transition service described in Salford?

A. Dr. Ritchie replied that it is difficult, and we need to be better at measuring success and demonstrating the impact. Clinical services need to understand why transition provision is important. We haven't got it right yet. Clinical Health Psychology for example is provided in good faith. We need to make a case to invest in joint clinics that result in engagement and growing service provision.

Q. How do we encourage life-course research rather than separate young person and adult research in this area?

A. Dr. Thabit replied that sometimes research is divided by age for clinical safety reasons and to ensure pharma safety. There do need to be more studies across age ranges and there is a recognition of the need for research in this area, such as research in healthcare models that focus on engagement rather than clinical models.

Q. How much work is happening for those with co-occurring conditions e.g. autism and ADHD?

A. Louise responded that much of the last year has been spent looking at CYP with co-occurring conditions and data is now available to track children through their GP records. The next steps would be to analyse the journey for those CYP and understand at what point we could have changed the journey for them.

Dr. Kothandaraman commented that she would be keen to see how Neighbourhood teams can address co-occurring conditions.

Dr. Thabit stated that we sometimes seem to be working in silos, and we need to move away from siloing conditions.

Q. Re. diabetes technology, as an adult patient I had to fight for this. It is easier to access in children's services. How do you manage technology?

Dr. Thabit acknowledged the age-defined guidelines which meant that children were prioritised, but not all adults were. At 18 years of age, the criteria for access changes. The National Institute for Health and Care Excellence (NICE) is trying to make this more streamlined. There is also pressure on adult services for investment in young adults to continue care from paediatrics, and also to try to meet the guidelines for adults. Each service needs to identify its own needs.

Q. The age of transition (transfer)- different teams accept CYP at different ages. They need to decide which service they go to and for someone with more than one service there may be different ages of transfer. In one area, 16–18-year-olds are 'dropped'.

A. Louise responded that there are legacy commissioning arrangements in place across the 10 areas in Greater Manchester, whereby services were commissioned in different ways. She acknowledged the challenges of addressing this commenting on commissioning intentions for community paediatrics, and the development of a single specification for Greater Manchester Child and Adolescent Mental Health Services (CAMHS), to align the provision. There are now opportunities to address this as a system through the Integrated Care Board.

Q. Given the financial deficit in the NHS, balanced with the NHS 10 Year Plan, what opportunities do we have to make this a reality?

A. Louise responded that the shift to prevention means we need to consider how we support the needs of CYP through some of the big GM projects such as Integrated Neighbourhood Teams (INTs), family hubs and the prevention demonstrator. We are mandated to do this together as a bigger system and the ICB blueprint enables us to develop our own solutions.

Dr. Ritchie emphasised the importance of recognising Adolescents and Young Adults as a group within population health and communicating this. Information should describe gaps in care and should not remain in silos but should be shared at clinical level and translated into needs.

Q. Is the ICB working with social care and education?

A. Louise responded that her job is to do this at leadership level and referred to a number of roles that work jointly across the ICB and Greater Manchester Combined Authorities (GMCA). Aforementioned projects (INTs, family hubs, SEND) and safeguarding reform all have a mandate to do this and work together. There are challenges around workforce and enabling them to work across the system, however the ambition is that we will ha ve a fully integrated system.

4. Sharing the Learning

During this part of the event, learning from different transition experiences was shared, including experiences of adolescents and young adults, and those of workforce delivering a transition service in Stockport.

4.1. Care around the person- journey through adolescence to young adulthood for a person with health, young adult panel facilitated by Manchester University Hospitals NHS Foundation Trust (MFT) Youth Service:

Sameer, Rosie, Grace and Ayub | young adults

Nicola Rigby, Rachael Pearson | MFT Youth Service

Q. What are your experiences of transition?

A. Transport is the biggest issue. Not knowing where you will be sent [in adult services]. You can be under different hospitals.

Started around 16 years and there isn't enough time. Consultants are busy and they don't have time for you. Adding one more thing to a schedule can be difficult to fit in around education etc. so don't leave it too late. Give us enough time to think about and to ask questions.

Recommendations to say to parents- set boundaries between young people and professionals. Some professionals don't see it helpful to have parents involved. They need to understand what you want out of appointments.

Advice to young people- It's not easy. Don't worry too much or overthink it. Be confident and ask questions. "If you don't ask you don't get!"

Q. Is there anything else universities can do to make life better?

A. Uni didn't understand, and support is only in place after 4 years.

Q. Is it because education just looks at education and not the health of the person?

A. This was a nursing course, so it was split.

Q. You mentioned about uncertainty and fear of falling off a cliff edge. What point should conversations start?

A. (1) Earlier. It felt rushed. The was a lot of expectation about independence in a short time period. Maybe about 14 years when you've just picked GCSE.

(2) It wasn't communicated that it would be a transition appointment. It should probably be about 13/14 years- not doing GCSEs but working up to them. You want to think about the future and education first. Parents know you better than doctors.

When you're an adult parents cannot advocate for you. It should be the patient's decision for the parents to be present.

(3) After GCSEs. I'd not had much medical experience until last year. It shouldn't be rushed. Around 16 years.

(4) Some skills can be developed earlier so when you're older you have the confidence and can use them, like making appointments.

4.2. The Stockport Diabetes Transition Young Adults Pilot – The impact of the MDT (including youth workers) in transition | Chris Bolland, Youth Worker, Michaela (Kyla) Howard, Diabetes Specialist Nurse (DSN)

Chris and Kyla described the work of the Stockport MDT for diabetes transition. The MDT was developed as part of a nationally funded pilot, originally for two years and extended for a further year. There were recruitment challenges for some posts such as dietitian and psychologist, so the core team consists of the Diabetes Specialist Nurse (DSN) and the youth worker. Key learning points were highlighted from the pilot to date and videos capturing AYA experiences of living with diabetes as a young adult were included in the presentation.

The goals of the team may not be the same as the AYA priorities. To address this, a feedback session was facilitated with the 235 young adults identified by the service, and they were asked what they would like to change. Actions that were implemented include:

- A phone hotline- AYA can contact the team by text, and WhatsApp has been successful for communicating with them. It also means information can be sent via this route. Letters and emails received no responses.
- Point of Care testing
- Clinics were taken into the local community to enable easier access.
- Clinic times were changed and arranged around the AYA, just for them.
- The youth worker role helps to 'break the ice' and the team starts to see 16-year-olds in paediatrics but do not take over their care.
- Lots of social activities were introduced that offer a level of peer support e.g. a football team, social events/ evenings for particular groups such as girls' group, informal get-togethers.
- A separate WhatsApp group was set up for the AYA with no clinical involvement which offers peer support. Some of the AYA have set up their own groups as well.

The team has linked with the eye screening clinic as this can be a challenge to achieve, and they have run joint clinics with great success. They also offer food bank support and have liaised with the Eating Disorder clinic to ensure referral pathways are in place. If anything has prevented AYA attending clinic, the young adult team has addressed this, and there has been significant success with the reduction of DKA admissions and engagement with AYA. The team acknowledged that some young adults find it difficult to leave the service at 25 years-old, and equally, it's difficult for the team to let them go.

Q. What strategies to the team use to 'wean-off' AYA?

A. They are honest from the outset about the provision and the fact that the service only runs up to 25-years of age, and that the support they offer is to enable the AYA to know what they are doing by this time.

Q. How do you address your work-life balance if you have a mobile phone?

A. It is difficult not to answer texts, but they need to switch off during holidays etc.

5. Get involved

There was lots of interaction during the event, with questions and answers about the various presentations, and for the two panels. This meant that the table discussions didn't happen as planned, however questions were circulated afterwards, and people were given the opportunity to submit their thoughts and ideas.

5.1. What does successful transfer look like to you and how do we achieve this?

- Well-planned transfer where YP and their families are supported, prepared and feel able to go to adult services.
- A young person feeling supported, by communication
- Would see the transition being a process and overlap from one service/organisation to another, would focus on the CYP/family needs rather than one size fits all.
- Need adult leads to engage
- Good communication and collaboration
- Uniform and collaborative working between Paediatric and Adult services. A wider national conversation and approach is needed, so that ALL NHS services work in line with each other at the point of transition. All NHS services transfer children at 18 years (or whatever age is deemed appropriate).
- Successful transfer should be seamless - it needs dialogue between the young person, their family and paediatric & adult services.
- A successful transfer would prevent a drop-in care. To achieve this all departments would have to work together.
- Patients feel empowered to manage their own health needs and trust the professionals involved in their care to facilitate this. By supporting patients with the adjustment from children's to adults' services, asking individuals what support they need rather than having a 'blanket policy'.
- Child at the centre of care, joined up services to provide seamless transition started age-appropriately for that child. We achieve this by involving the child in decision making and asking what would make their transition 'good' for them; having youth workers to support, joining up with other MDT if the child has other co-morbidities, to listen and support the child, patient/carer throughout their journey. To involve the education sector in planning for the future.

5.2. Finance and commissioning decisions- how do we influence the ICB as a strategic commissioner for adolescent and young adult health care through transition?

- Ensure young people are included and their thoughts and contributions are listened to.
- Need data and YP voice to demonstrate the value to commission the capacity for adult services to manage the transition.
- Data
- By collaborative support, securing cost-effective outcomes.
- Strong leadership and innovation
- Need to ensure that transition, and pathways for 16/17 yr olds, is included in service specifications and therefore specifically commissioned within services.

Focus on person-centred commissioning and commissioning for outcomes - if we can define the outcome required for these cohorts as part of the service specification then this can be monitored.

- To provide data of the difference between transition and non-transition.
- Case studies/patient stories, provide data to demonstrate how effective services impact patient care/outcomes.
- Present local data/evidence on drop-off in engagement with services post-18 (e.g. fewer outpatient appointments kept, more A&E attendances).
- Use case studies from Greater Manchester young people to show human impact.
- Share examples of cost savings from well-managed transitions (e.g. fewer emergency admissions in diabetes/epilepsy when transition pathways are robust).
- Utilising the Greater Manchester ICB Joint Forward Plan which highlight priorities around children & young people, mental health, long-term conditions, and health inequalities.
- Show how transition improvements tick multiple boxes: adolescent health, early intervention, mental health resilience, long-term condition management.
- Demonstrate engagement with patients and the public - co-production model
- Create or link to a Youth Advisory Group that can present to the ICB about experiences of transition.
- Use direct testimonies alongside data to strengthen the case.
- Collaborate with paediatricians, adult clinicians, schools, social care, voluntary organisations to give a united ask.
- Influence via the Children and Young People’s Boards that often sit under the ICB structure.
- Align with NHSE Transition Frameworks and NICE guidance, so the ICB sees this as national best practice they should comply with.
- Suggest the ICB fund pilots of best practice transition models (e.g. transition coordinators, joint clinics, peer mentoring).
- Offer to evaluate them and feedback cost–benefit evidence.

5.3. What would you like to see as a focus for a follow-up workshop? E.g. developmentally appropriate inpatient care, mental health and wellbeing and transition.

- Yes - all of the above topics would appeal to me.
- More regarding children with complex long-term health conditions. The event was very focused on specific conditions. Maybe parents point of view? Also, information regarding the future of transition and how this will change going forward.
- What can good practice look like and achieve, young adults' voices where there has been a positive transition and how this has helped them manage their LTC. Maybe a parental experiences who's YP doesn't have the ability to advocate for themselves e.g. due to cognitive impairment and what's worked well.
- Adult health care
- Mental health and wellbeing
- Developmentally appropriate Inpatient care -i.e. Adolescence wards.
- I would like to see something on services for 16/17 yr olds in general, not just those with long term conditions, as they often get bounced between paediatric and adult services with no-one willing to take responsibility for them. I would welcome a discussion on how we put in place appropriate pathways for this cohort.
- The impact on wellbeing during the transition period.
- Community/therapy services transition.
- Young people's voices: panel or co-facilitators sharing lived experiences.

Case studies: one successful transition, one where it broke down — what can we learn?

Breakout groups: design "the ideal pathway" for a young person with a long-term condition.

5.4. What action will you take away and commit to following today's meeting?

- Consideration of the comments and thoughts of the young people who spoke today.
- Ensure young people have started their transition journey early.
- Role of the Youth Worker as being a conduit to this process, and also a need to have data to demonstrate how a 'good' transition results in young people using UEC services or out of hours less as they are well connected to their 'adult' teams.
- Share far and wide however need adult leaders.
- Support, and early young adult education
- To Improve Transfer of Children to adult services, using the voice of young people going through transition.
- Importance of commissioning appropriate services for young adults.
- Explore the use of transition programmes such as Ready Steady Go and Alderhey 10 steps and whether these fit within our service.
- Commit to working and influencing to get more young voices heard in health system spaces.
- To listen to the voice of the child around the age they would like to start their transition

6. Conclusion and recommendations

The information gathered from this event has been insightful and will support planning for transition provision to ensure our adolescents and young adults are not left to 'free-fall' during their move into adult services. Rather they should be provided with the knowledge, information and support that will enable them to 'parachute' into this unfamiliar territory, with the right landing gear to enable adult services to receive them and nurture them until such a time that they are able to manage independently, and according to their individual ability. We will arrange follow-up workshops for all who are interested to progress discussions in a more focussed way, and in line with the suggestions made by attendees.

6.1. Recommendations

These recommendations are for consideration by organisations within the Greater Manchester health and care system, including provider and commissioner organisations, voluntary, community, faith and social enterprise (VCFSE) sector organisations.

1. Adolescent and Young Adult (AYA) voice should be at the heart of decision-making about transitions including who should be involved, the age at which transition conversations begin, and where they transition to.
2. NICE guidance states that transition planning should start from year 9 (13/14 years). There was a general consensus that transition discussions should start as early as possible and therefore organisations should ensure AYA have started their transition journey early.
3. Services should consider the use and interpretation of terminology and how this is applied to service provision with the ultimate aim of avoiding transfers of care and adopting transition processes that ensure continued engagement and continuity of care. For some AYA, transitions adult services are more complex as they may have multiple services involved in their care, or there may not be equivalent adult services to the paediatric services they are transitioning from. Support to navigate this complex healthcare system should be offered until the AYA is familiar with and comfortable with their new care provision.
4. Health should be considered in its broadest sense and non-clinical models such as youth workers as key workers should be considered to address needs that may prevent access to healthcare.
5. Some AYA may transfer to services out of area e.g. when they leave for university. Services should consider how they will communicate with out of area services, and educational establishments to ensure the AYA remains engaged with services and compliant with their healthcare regime. Consideration should be given to the AYA voice regarding from where they wish to receive their care in these cases, e.g. remaining in their hometown services, or services in the area where they receive their education.
6. Transport may be problematic for an AYA who is no-longer attending appointments with their parents/ carers. Consideration for where services are delivered should include easily accessible for a young adult without their own transport.
7. Parents and carers have needs and may require support as their young adult becomes more independent of them. Services should offer a means of accessing parent support (groups) and remaining involved with their AYA care, if the AYA would like that.

7.2. Next steps

A series of workshops will be organised to discuss more specific transition issues as identified in the feedback to include:

- What support is needed for AYA with long-term conditions (and their parent/ carers and families) to keep them engaged with services, and to manage their condition into adulthood?
- Transition and transfers for AYA with complex conditions and/ or multiple morbidities.
- Developmentally appropriate care for 16-17 years including inpatient, outpatient and A&E care.
- Palliative and End of Life Care transition workshop suggested by email.

A common thread throughout will be the voices of AYA, and we will try to incorporate more parent/ carer voice within the workshops.

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Glossary of Acronyms

Acronym	**Full Term**
A&E	Accident and Emergency
ADHD	Attention Deficit Hyperactivity Disorder
AYA	Adolescents and Young Adults
CAMHS	Child and Adolescent Mental Health Services
CVD	Cardiovascular Disease
CYP	Children and Young People
DKA	Diabetic Ketoacidosis
DSN	Diabetes Specialist Nurse
GIRFT	Getting it Right First Time
GM	Greater Manchester
GMCA	Greater Manchester Combined Authority
HbA1c	Haemoglobin A1c (Glycated haemoglobin) measures average blood sugars over the last 2-3 months
ICB	Integrated Care Board
INT	Integrated Neighbourhood Team
JFP	Joint Forward Plan
LTC	Long Term Condition
LTFU	Lost to Follow-up
MDT	Multidisciplinary Team
MFT	Manchester University Hospitals NHS Foundation Trust
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
RMCH	Royal Manchester Children’s Hospital
SCN	Strategic Clinical Networks
SEND	Special Educational Needs and Disabilities
UEC	Urgent and Emergency Care
YARN	Young Adult Renal Network
YP	Young Person/ People