Greater Manchester Integrated Care Partnership

Greater Manchester Diabetes Transition Strategy

2024-2027

Introduction from Dr Hood Thabit and Dr Chris Cooper

The Greater Manchester Integrated Care System wants to ensure all children living with diabetes in Greater Manchester have the best possible transition experience and care available to them. The Greater Manchester (GM) Diabetes Network and the Diabetes Board are supporting development of this strategy that will set out the ambition for the next three years.

The strategy defines the vision, aims and outcomes that we hope to achieve across the GM system working with a variety of stakeholders and partners.

We will encourage local services to a adopt service specification which incorporates the necessary components of care and the recommendations in this strategy whilst supporting flexible local service delivery models.

This document was developed jointly with clinical providers from all ten localities in GM. Feedback from young people living with diabetes was also sought as part of the development of this document and incorporated into it.

Reportable outcomes as outline by the strategy will support local commissioners and local care organisations to review their local service provision and requirement to ensure the delivery of high-quality diabetes transition in line with the 2020 NHS GIRFT diabetes report[1].

Achievement of the objectives set out in this strategy has the potential to drive future savings in through reductions in acute complications and hospital admissions, and to reduce the long-term risk of diabetes complications.

We are delighted to have this opportunity to develop this document and we hope that it will help us to deliver improved outcomes for our patients.

Dr Hood Thabit

Consultant Diabetologist & Honorary Senior Lecturer

GM Clinical Lead for Diabetes Transition

Greater Manchester & Eastern Cheshire Strategic Clinical Networks

Dr Chris Coooper

Consultant Paediatrician

GM CYP Clinical Advisor for Diabetes

Greater Manchester & Eastern Cheshire Strategic Clinical Networks

[1] Diabetes GIRFT Programme National Specialty Report - www.gettingitrightfirsttime.co.uk/wp-content/uploads/2020/11/GIRFT-diabetes-report.pdf

Transition of Care Definitions

Transition: is defined as "a multi-faceted, active process that attends to the medical, psychological and educational/vocational needs of adolescents as they move from child to adult centred care" (Blum 1993)[2]. It is now advocated that this process starts in early adolescence (NICE, 2016, DH, RCH)[2].

Transfer: is the event of leaving paediatrics and entering adult services within primary/ secondary/tertiary care.

It is now advocated that the process of transition starts in early adolescence.

[2] Transition from children's to adults' services for young people using health or social care services, February 2016 nice.org.uk/guidance/ng43

Overview of the Diabetes Transition Strategy

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The strategy aims to improve further the diabetes transition services across Greater Manchester and Eastern Cheshire to meet the expectations of young people and their families. The vision that underpins this strategy will determine the network plans over the next three years.

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The aims and mission of the strategy are to deliver the best experience for young people living with diabetes and their families, in accordance with published national guidelines and diabetes transition service specification[3].

The strategy was developed through a process of briefings and project scoping exercise which informed the network of current practice among diabetes transition service across Greater Manchester and Eastern Cheshire as well as the challenges faced by each service. The findings from the scoping exercise were consolidated through a discussion and feedback forum from healthcare professionals and network members involved in delivering diabetes transition at their local institution, as well as user feedback from Youth Forums and Diabetes UK.

The successful delivery of this strategy will depend on close partnership working with integrated care systems (ICS), Greater Manchester Health and Social Care Partnerships and Manchester Local Care Organisation, schools and colleges, local networks, voluntary sector organisations, general practitioners and other health and social care providers.

The objectives and implementations under this strategy will be afforded to young people with diabetes in a developmentally appropriate manner.

[3] Diabetes Transition Service Specification, January 2016 diabetes-transition-service-specification.pdf (england.nhs.uk)

Vision and Aims of the Diabetes Transition Strategy

Vision and Aims of the Diabetes Transition Strategy

Our Vision

To have young people with diabetes in the Greater Manchester and Eastern Cheshire area to receive the care that is responsive to their needs.

Our Aims

- To provide safe, effective, developmentally appropriate transition process and transfer (handover) from children's services to adult services for all young people with diabetes.
- To ensure young people and/or carers experience a transition process that equips them with the required knowledge and skills to manage their diabetes in partnership with the adult services.
- To provide care, through adult diabetes, for young people and their families in a developmentally appropriate way without any loss in the quality of services, on-going engagement, or patient experience.

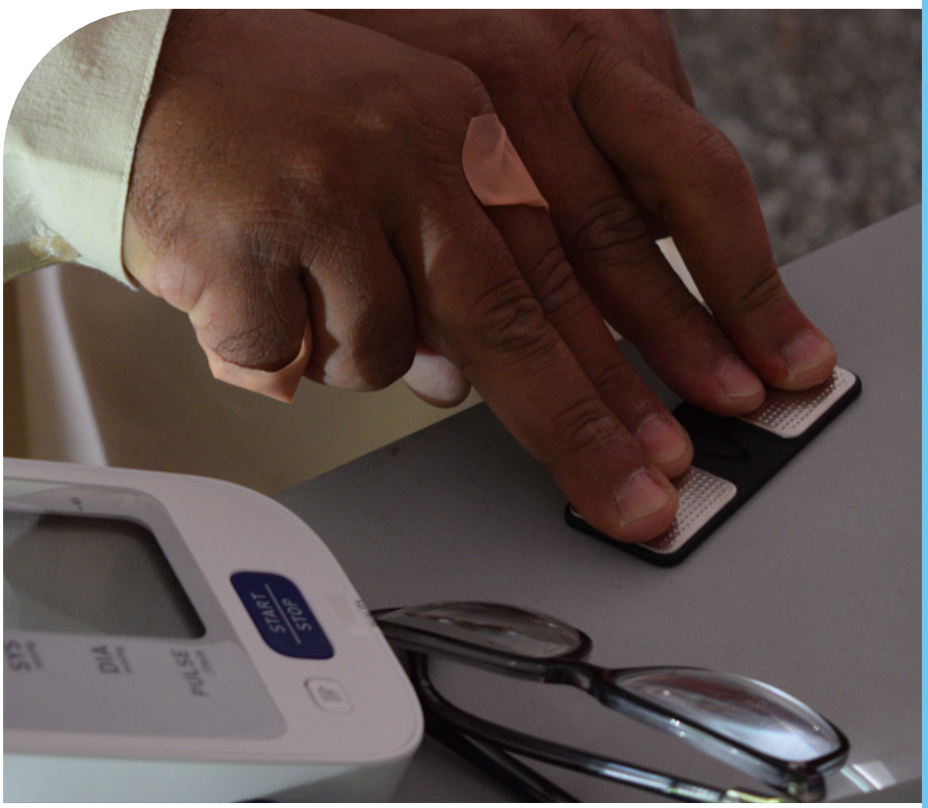
We aim to provide care in a developmentally appropriate way.

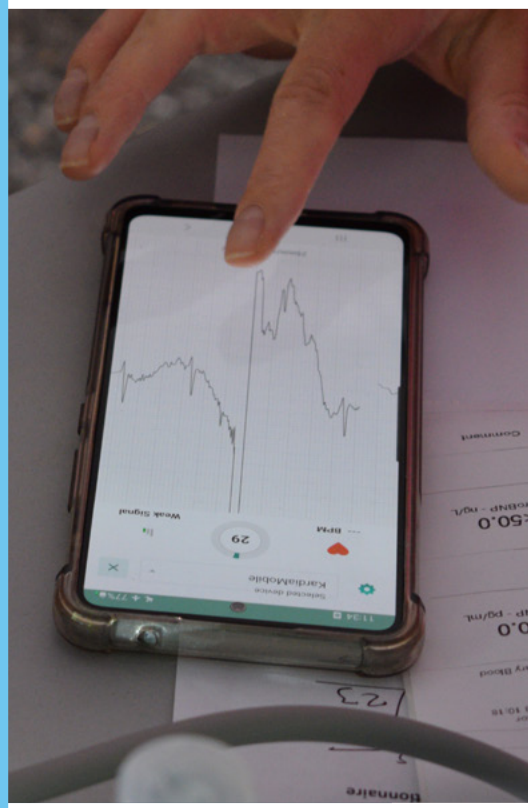
Challenges

Challenges

As part of the development of this strategy, a number of challenges were identified that could prevent this strategy being fully adopted across Greater Manchester.

- Staff numbers and retention – staff retention remains an ongoing challenge within the local systems.
- Staff training – ensure staff know what seamless and personalised transition looks like.
- No dedicated or additional funding for diabetes transition – paediatric and adult diabetes services are funded differently, and there is currently no money dedicated for diabetes transition.
- Transition generally not being specified in adult diabetes services job plans and workload – transition is not seen as a priority, comparatively to other requirements, and does not always form part of clinicians' job plans.
- Lack of youth workers and clinical psychology support in most centres delivering diabetes transition.





Objectives

Objectives

The six objectives below highlight the core areas the strategy will concentrate on and the implementation strategies. These objectives were reviewed and approved by young people in Greater Manchester.

1. Objective: Ensure every young person with diabetes who is able to participate in decision-making be involved in discussions and make informed decisions about their diabetes care.

How we will achieve it:

1.1. Involve the young person and their family, while ensuring the young person has enough autonomy, in their transition and transfer plan early in their clinical journey, utilising locally developed or adapted programme documents and treat them as equal partners in the process.

1.2. Involve the young person in decisions related to their current and future use of diabetes technologies (e.g., continuous glucose monitoring, insulin pump) and other therapies.

1.3. Utilise youth forums which have representation from young people for peer support, and digital programmes to support diabetes self-management in young people (e.g., Digibete, Diabetes My Way).

1.4. Acquire feedback from the young person whether the transition process has helped them achieve their agreed outcomes and feedback these outcomes to the young person, their parents/carers and other clinical teams (e.g., primary care).

1.5. Review the transition planning with the young person on a regular basis (at least annually).

1.6. Perform survey among young people attending the service and their parent/carers for feedback on their experiences with the diabetes transition service.

2. Objective two: There will be designated a Diabetes Transition Team with appropriate infrastructure and key professionals identified to support the transfer of every young person from children's to adult diabetes services.

How we will achieve it:

2.1. Each local organisation to identify individual(s) with responsibility to lead the diabetes transition team.

2.2. Each local organisation to review job planning and roles required for paediatric and adult diabetes teams to deliver diabetes transition as recommended by national guideline (NG43)[4] and Diabetes Transition Service Specification[5].

2.3. Each local organisation to support diabetes transition by providing infrastructure such as designated area and clinic space appropriate for young people.

2.4. Each local organisation after a discussion with young person, to allocate key worker(s) to provide support and coordinate the delivery of diabetes transition. The key worker could be a diabetes consultant, diabetes specialist nurse, or other health care practitioner with whom the young person has a meaningful relationship. The key worker(s), agreed by the young person, will initially be someone based in paediatric services but will hand over their responsibilities and ensure relevant information such as any safeguarding concerns are shared to the professional in the adult diabetes service when appropriate.

2.5. Each local organisation will provide the young person with a transition pack, containing useful information regarding transfer of care and contact details (e.g., clinic information, offer ward visits, length and frequency of adult appointment etc.)

2.6. Each local organisation to support diabetes transition by regularly participating in local/national audits of their care processes, outcomes and other quality improvement programmes.

[4] Transition from children's to adults' services for young people using health or social care services, February 2016 http://nice.org.uk/guidance/ng43
[5] Diabetes Transition Service Specification, January 2016 diabetes-transition-service-specification.pdf (england.nhs.uk)

3. Objective three: All staff involved in diabetes transition and transfer of care will have training and support to enable them to care for young people and manage transition of care effectively.

How we will achieve it:

3.1. Ensure all staff involved have access to training relevant to caring for this population, which may include but not limited to signposting team members to a competency framework specific to diabetes transition issues.

3.2. Ensure all staff involved in transition have access to training (face to face and e- learning), dependant on need, which covers:

- Effective communication with young people
- Young people's development
- The legal context and framework related to supporting young people through transition, including their rights to confidentiality, consent and safeguarding
- Special educational needs and physical disabilities
- Learning disability
- Mental health
- Autism
- Youth friendly health services
- How to involve young people, carers and families in their care, development of services and work in partnership
- Identifying a diabetes transition champion within the team

4. Objective four: Every young person transferring across to the adult diabetes team will have a diabetes transition programme and documented transition plan to ensure relevant professionals have access to essential information about the young person's transition journey and needs.

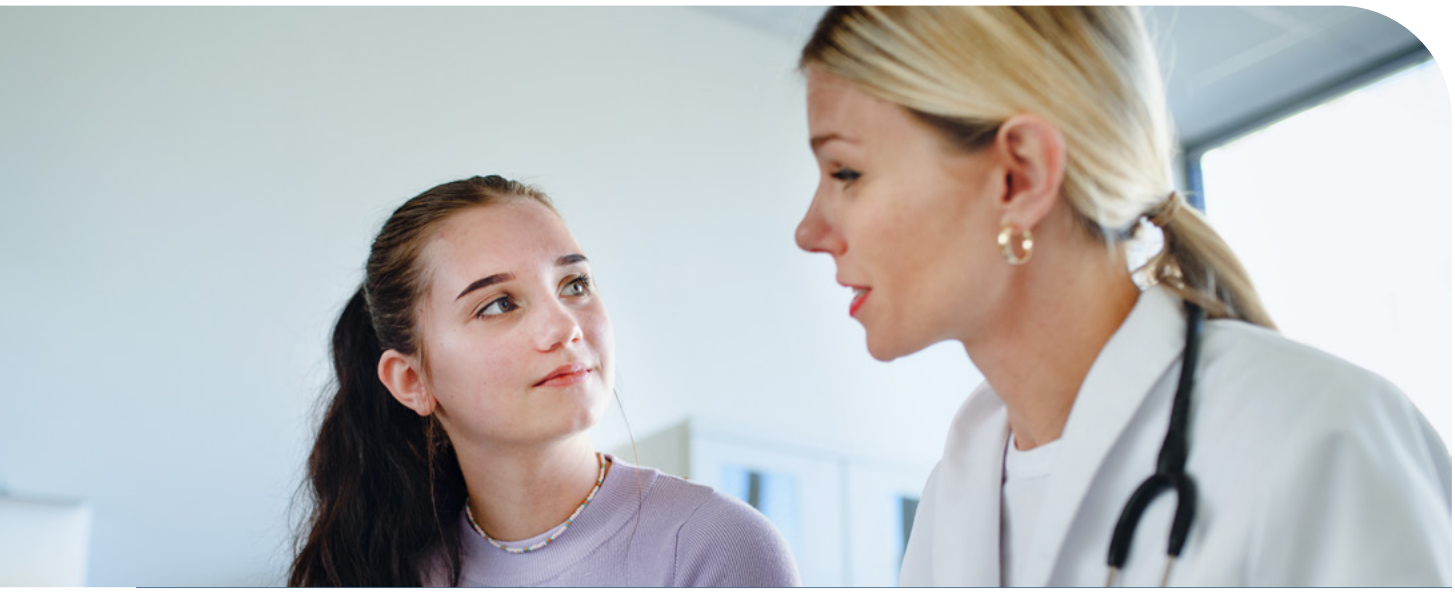
How we will achieve it:

4.1. In consultation with the young person and their parents/carers where appropriate, to complete a diabetes transition programme and documentation (e.g., Ready Steady Go) to address outcomes including those related to specific diabetes self-management goals.

4.2. Review the documentation on an on-going basis to ensure it meets the needs of the young person and their diabetes care.

4.3. Sharing of the documentation and output with healthcare professional involved in the young person's transition planning, and with the young person themself.

4.4. Recognise that there is a possibility of the young person becoming disengaged with the diabetes team during this process and that there is a need to ensure shared records of care are maintained with both secondary and primary care. This may be through a comprehensive letter and plan to primary care, to enable primary care to re-refer to adult services when the young adult is ready.



5. Objective five: Every young person with diabetes who is at higher risk of disengagement and complications to be identified during transition and following transfer to adult care.

How we will achieve it:

4.1. Engage with young people as individuals to discuss personal strategies that will enable them to reduce their risk of disengagement, complications and unplanned hospital admissions.

5.2. Allocate additional support (through key worker, see 2.4) if the young person requires further input to mitigate their risk, either through clinical consultations or involvement of a Youth Worker and to include the young person in the process.

5.3. Identify the support available to the young person, family or carer by signposting to resources which may include but not limited to e-learning/ online digital programmes (e.g., Digibete, Diabetes My Way), Psychology, Youth Worker service, Support Groups or Youth Forums.

5.4. Establish a clinic database or tools to identify/stratify at-risk individuals that can be integrated into local clinical pathways and policy, such as high HbA1c Clinic, Clinic Report Page to audit sensor glucose outcomes, Folic Acid Supplementation advise to females of reproductive age, Diabetes MDT with Psychologist.

5.5. Undertake regular audits of clinic attendance and waiting list of Transition Clinic (and Young Adult clinic if appropriate) to identify organisational challenges where changes and support are needed.

6. Objective 6: The organisation will work closely with primary care colleagues; ICS, voluntary sector organisations, schools and colleges, local networks, other health and social care providers, ICB and Greater Manchester Local Care Organisations, and offender's team to ensure the Diabetes Transition process is inclusive and efficient.

How we will achieve it:

6.1. The Diabetes Transition Strategy will be shared with all partners.

6.2. Systems and practices will be jointly reviewed to identify where changes and support are needed.

6.3. Engage and involve all practitioners providing support to the young person and their family or carer, including the primary care practitioners.

We will engage and involve all practitioners providing support

User feedback

User feedback

To ensure this strategy met the needs of those whose experience will be impacted by this document, feedback from young people was sought. We collaborated with the Youth Forum at Manchester University NHS Foundation Trust and Diabetes UK.

Number of focus groups took place to discuss the proposed objectives and the experiences of those preparing for transition, currently going through transition and those who already transferred to adult services. We also collected views of young people who are not living with diabetes, but experienced other healthcare transition services. This is to make sure we are approaching diabetes transition as a whole process.

We are pleased to say the Objectives in this strategy were approved and supported by young people who took part in the user focus group meetings and forum.

We will make sure we approach diabetes transition as a whole process.

Our Mission for the Diabetes Transition Strategy

Mission Statements

1. We will ensure that every transition service has the young person at its centre and that every young person has the right to be involved in the decision-making care process.
2. We will help improve the availability of a Transition Team that is able to support the transfer of every young person from children to adult diabetes services.
3. We will support the need for all staff involved to be provided with opportunities to develop their skills which are needed to deliver the best possible transition service.
4. We will work to help improve access to essential information related to the young person's care during transition, and ensure these are appropriately shared with relevant professionals when they transfer to the adult service.
5. We will be mindful of the challenges faced by young people during this challenging phase in their life, and will do whatever we can to support strategies that can help those who are at higher risk of disengagement.
6. We will work collaboratively across different organisations in the Greater Manchester and Eastern Cheshire area so that we can commit to delivering the principles of our strategy.

The outcomes we want to achieve

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The outcomes we want to achieve are listed below and will be captured through person-reported surveys and clinic data available across the diabetes transition services:

1. **An improvement in young person-centred satisfaction through appropriate surveys or validated measures (e.g., Satisfaction with Life Scale).**
2. **An improvement in HbA1c levels and other matrix of glycaemic control (e.g., sensor-based time in target range).**
3. **A reduction in the proportion of young people not attending consultations with the Transition Team.**
4. **A reduction in the proportion of young people not being transferred at the appropriate period.**
5. **A reduction in the proportion of young people having acute diabetes-related hospital admissions.**
6. **An improvement in the documentation of all health-related topics discussion (e.g., alcohol, illicit drugs, adult services, smoking, contraception, complications).**

"Our population continues to experience higher than national instances of heart disease, diabetes and other lifestyle related illnesses."

References

References:

Diabetes Transition Service Specification, January 2016 diabetes-transition-service-specification.pdf (england.nhs.uk)

Diabetes GIRFT Programme National Specialty Report - www.gettingitrightfirsttime.co.uk/wp-content/uploads/2020/11/GIRFT-diabetes-report.pdf

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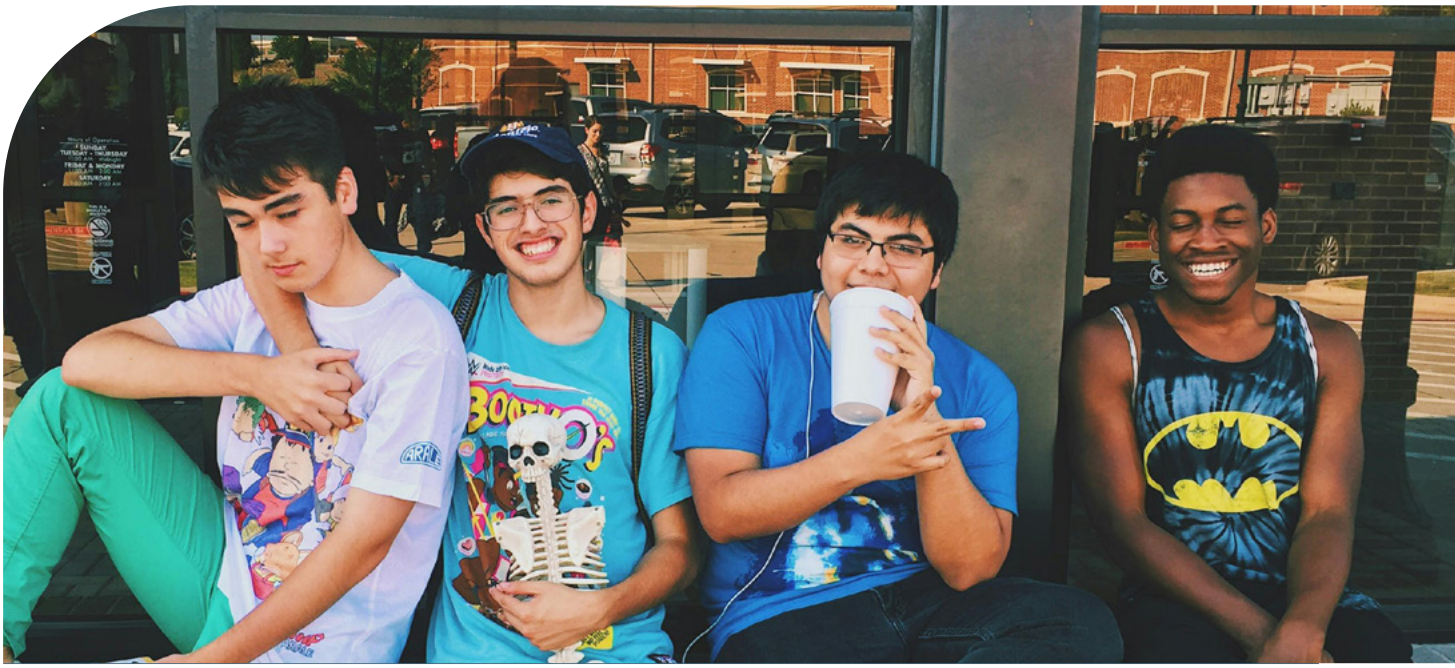

Appendix A: User Feedback on Greater Manchester Diabetes Transition Strategy Objectives

This document is an active document and will be updated when/if more feedback is received.

As part of development of the strategy document, feedback was sought from young people, on the six objectives. This was to ensure; the young people's voices were heard, and the publication of the document did not impact negatively on young people using diabetes services in Greater Manchester.

The user feedback was completed in collaboration with Manchester University NHS Foundation Trust and Diabetes UK.

To ensure variety of feedback, we took the following approaches:

1. **Youth Forum at Manchester University Foundation Trust** – we attended youth forum meeting in MFT, where we had representation from young people, some living with diabetes, some with other long-term conditions. They reviewed the six strategy objectives and provided verbal and written feedback.
2. **Diabetes UK user group** – live online user feedback group was set up by DUK, for young people with diabetes. During the live session feedback was provided on the strategy objectives as well as general discussion around the transition experience.
3. **Online survey** – online survey was set up, to gain feedback on the six objectives. This was shared widely on social media, newsletters, with users via DUK and Youth forum. This was opened to people living diabetes as well as their families/carers.

The ask

- Review the six objectives and tell us if these meet the needs of young people with diabetes and their families.
- If there was one thing the NHS could do to support your transitioning process, before you were transferred from children to adult services what would it be.

The objectives discussed

1. Ensure every young person with diabetes who is able to participate in decision-making be involved in discussions and make informed decisions about their diabetes care.
2. There will be designated a Diabetes Transition Team with appropriate infrastructure and key professionals identified to support the transfer of every young person from children's to adult diabetes services.
3. All staff involved in diabetes transition and transfer of care will have training and support to enable them to care for young people and manage transition of care effectively.
4. Every young person transferring across to the adult diabetes team will have a diabetes transition programme and documented transition plan to ensure relevant professionals have access to essential information about the young person's transition journey and needs.
5. Every young person with diabetes who are at higher risk of disengagement and complications to be identified during transition and following transfer to adult care
6. The organisation will work closely with primary care colleagues; ICS, voluntary sector organisations, schools and colleges, local networks, other health and social care providers, ICB and Greater Manchester Local Care Organisations, offender's team to ensure the Diabetes Transition process is inclusive and efficient

The feedback

All the below feedback was incorporated into the strategy document and lead to updated objectives.

Objective One

- Like this objective. When going through their own transition, felt parents were the ones who had the conversation about transition with the staff rather than the young person.
- Good it contains part about the technology as young people are worried about transferring, would they lose technology when they transfer?
- If they qualify for example for hybrid close loop as children, but as an adult they wouldn't, what would happen? Would they get to keep it?
- It's good objective, as it covers pre, during and post transition
- How do we still give the young person enough autonomy to make decisions about their diabetes care whilst still appreciating the parents'/carers' role in providing guidance
- I think this will be a really good reflection for the young person as well as the clinical team, and also like how the measure of success is based on the patient's agreed outcomes
- Would still want parents involvement.
- Talking about Tech – Get to trial different things.
- Understand that Young people have a life outside of diabetes.
- Want to meet the Adult Dr beforehand.

Objective Two

- Like to have roles in place, identification of key workers (the difference of having the one person who knows you, and knows the family is really important)
- Make it more accountable
- Point 3 (Each local organisation to support diabetes transition by providing infrastructure such as designated area and clinic space appropriate for young people) – this is not being done enough, went straight from paediatric clinic to adult clinic. Sitting in waiting room with other adults, who may have different complications did not make it nice experience.
- Should be standard to have transition clinic area.
- Point 2.4.(The key worker could be a diabetes consultant, diabetes specialist nurse, or other health care practitioner with whom the young person has a meaningful relationship) - This will be really beneficial for the young person, but what is seen or recognised as 'meaningful'
- Engage Youth Worker? – Want it to be who knows you the best.
- Can you say "I don't want you on my Transition team?" e.g. Can you have a certain nurse/doctor?

Objective Three

- Like it. It's so important how staff talk to people, staff knew how to talk to me as a person, not just as a diabetes patient.
- Staff need to make sure they are not condescending
- Transition is very vulnerable time for young people, they have other things on their mind, diabetes is just one of them.
- Is the training going to be mandatory or optional?
- Point 3.2.(Ensure all staff involved in transition have access to training (face to face and e- learning), dependant on need, which covers) – This sounds amazing
- Specifically, what does the training entail?
- How do we evaluate the training?
- Effective communication – clear understanding
- Leaflet for young people about who to talk to about Transition
- Understanding meaning of young people's development
- Any aid for mental health? What services are provided?

Objective Four

- Never had any documentation, there was no plan
- Sharing information with everyone is very important
- It's important having documentation and implementing it, talking to young person, prepare them well
- University students, move to other areas, feeding into shared care record is very important
- Good understanding of young people's lifestyle.
- Clear understanding delivered to young people.
- Young person's access to Transition documents. Can they review it?

Objective Five

- One of the most important objectives.
- Moving to university, parents are not longer involved
- Most appointments are about HbA1c control, should be about more than that
- Deprivation
- Would the person who is disengaged, know they are identified as disengaged person?
- 'If young person requires' give option to patient, if they want a youth worker (reinforces individual).
- At what age/stage/point do you give a Youth Worker?
- Support groups, residentials.

Objective Six

- Important objective
- Connect the dots, Pharmacy etc. are important for people with diabetes, schools etc.
- This wide network of support will surely be appreciated by the young person!
- Include a review date.
- Transition strategy to be resent with every update.
- Efficiency – Write in document how they're establishing/achieving the efficiency.
- Offenders team – clarify who they are.

Overall Feedback

"Overall, I think it's clear that the strategy is implemented for children and young people and that the clinical team will be working in their best interests. I really like how the document outlines a holistic approach when considering the young person's diabetes care, especially when talking about personal strategies for the young person to reduce the risk of disengagement, as the young person is not considered as a patient but as a unique individual."

"How will the efficiency of the diabetes transition process be measured? Will this be based on the surveys collected from the young person/parents/carers?"

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