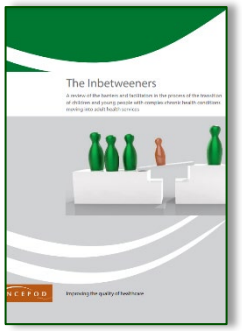

The Inbetweeners

A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions moving into adult health services.

NCEPOD Stakeholder meeting

BACKGROUND

The NCEPOD 2023 report, The Inbetweeners identified 5 key areas, informed by 11 recommendations that needed addressing to improve the pathway of care young people moving from child to adult health services. Just over one year on from the release of the report a stakeholder group met to discuss progress since the report, changes that have been made locally based on the recommendations, and to highlight those key areas that need further work to implement improvements.

KEY AREAS

1. MAKE DEVELOPMENTALLY APPROPRIATE HEALTHCARE CORE BUSINESS FOR ALL INVOLVED

This would ensure that transition and transfer planning is embedded into everyday healthcare by all the teams involved.

2. INVOLVE YOUNG PEOPLE AND PARENT/CARERS IN TRANSITION PLANNING AND TRANSFER TO ADULT SERVICES

This would put young people at the centre of their own care, and they could support improvements in the transition service.

3. IMPROVE COMMUNICATION AND CO-ORDINATION BETWEEN ALL SPECIALTIES

Clear communication between all specialties across multiple teams will stop the young person falling into a gap between services.

4. ORGANISE HEALTHCARE SERVICES TO ENABLE YOUNG PEOPLE TO TRANSFER TO ADULT SERVICES EFFECTIVELY

This would ensure there is a direction for every young person moving to adult services and ensure receiving services/GPs are prepared.

5. PROVIDE STRONG LEADERSHIP AT BOARD AND SPECIALTY LEVEL AT ALL STAGES OF TRANSITION AND TRANSFER

Strong leadership is needed to implement a transition service that ensures every young person receives the care they should expect.

PROGRESS

Recommendation

Develop a personalised transition plan with each young person who will need to move from child into adult healthcare service. Give the young person and their parent/carer access to this plan.

Target audience: All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team

Local examples of practice

- Transition plans have been made available on the electronic patient record, which all specialties can add to. These can be modified, for example in one organisation, these have been adapted to ask questions around consent, confidentiality, admission preferences, and participation in research for patients aged over 16 years.
- Health passport training implemented, and tweaks to existing health passports to develop a paediatric/young adult passport.
- Transition tab in Epic.

Challenges

- Engaging all the relevant teams involved across all organisations.
- The use of different electronic systems across different organisations.
- Ensuring all relevant clinicians are aware of the existence of transition plans.
- Identifying who is responsible for the plan and taking it forward.
- Including everything needed on the plan.
- Time constraints in clinic appointments to complete the plan.
- Engagement from IT

Recommendation

Copy young people and, where appropriate, their parent/carer into all correspondence regarding ongoing healthcare needs.

Target audiences: All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team

Local examples of practice

- The development of simple adaptable templates that clinicians can download and use, for example a template letter that can be sent from the paediatrician to the GP regarding arranging an annual health assessment, and a letter that the paediatrician can send to the GP regarding transition. These can be further developed to ensure the letter is sent to the patient as well as the relevant clinicians. The clinicians sending the letters still have control over the content so they can be adjusted for language etc.
- Making it an organisational requirement that CYP ≥16 years of age need to be copied into any correspondence.
- Adding a tick box to paediatric outpatient proforma's to remind teams to ask the CYP if they want to be copied into correspondence about them.

Recommendation

Hold joint transition clinics for young people moving from child into adult healthcare services, involving healthcare staff from the young person's paediatric team and the adult service(s) they will move to.

Target audiences: All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team and primary care

Local examples of practice

- The appointment of an administrator who is also a transition coordinator has enabled the tracking of the cohort of patients who are moving from child to adult health services, which helps with the setting up of joint clinics. This was achieved through the repurposing of the administration team rather than through receiving funding for the role.
- The identification of holistic elements of care (i.e., education) that could be delivered jointly across teams.
- Complex case joint clinics to see any young people looked after by three or more different specialties. This enables links to be made with adult intensive care.

Challenges

- Transition clinics are set up in each specialty but there is variation across specialties (and even within specialties) as to how these function and run.
- The time between clinics can mean that even if the adult clinicians see the patients prior to transfer, they only subsequently see the patient again a year later.
- The lack of clinical coding in transition is a barrier in arranging clinics.
- There is limited funding available to run joint transition clinics, and where funding isn't available, they are often dependent on the passion of the clinicians involved.
- Clinics are more challenging to run across sectors (i.e. hospital and community care), and this can often lead to challenges in accessing equipment.

Recommendation

Request input into the multidisciplinary team (MDT) for young people with ongoing healthcare needs.

Target audiences: All members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team

Local examples of practice

- The setting up of adult focused MDTs for CYP with complex conditions, not looking specifically at transition but recognising it as an ongoing care need.
- Being creative with the elements of the MDTs that work well in paediatric services to provide the same function in adult care. For example, adapting job roles for AHPs with an interest in paediatrics working in adult services to take on extra elements of care that are already embedded in paediatric rheumatology services.
- The development of an MDT for complex patients who need regular access to HDU/ICU. This has led to the development of a bespoke pathway which enables the patients to bypass the emergency department.

- Having a lead nurse for transition is key to the running of successful MDTs in terms of coordinating care with other Trusts/Health Boards and across sectors and identifying patients who will be moving from child to adult health services at the right time.

Recommendation

Involve primary care throughout the transition process from child into adult healthcare services.
Target audiences: Primary care and all members of the multidisciplinary team caring for the young person in child health services and the adult health services that the young person will move to, supported by the trust/health board transition team

Challenges

- Getting the terminology right
- Coding it one of the biggest challenges. Without coding it is difficult for GPs to identify who is moving from child to adult health services.

Recommendation

Implement an overarching trust/health board transition policy for all young people with ongoing healthcare needs.
Target audiences: Executive boards and clinical leads of all trusts/health boards, with support from the transition team

Local examples of practice

- Developing an overarching policy has been useful in raising the importance of transition locally, and it raises the awareness that all specialties need to be involved. It has also been useful to host this on the intranet so that everyone can access it. Young people have also been involved in the development of this.
- The development of a transition strategy, co-designed with young people. This is a one-page document available on the intranet

Recommendation

Ensure staff in all organisations complete training in developmentally appropriate healthcare and the transition from child into adult healthcare services. The content should be tailored to the job role and the degree of involvement with children and young people.
Target audiences: Executive boards and clinical leads of all trusts/health boards, with support from the transition team

Local examples of practice

- Monthly transition champion training, either on Teams or face-to-face. The professionals who attend find it useful.
- The implementation of training in developmentally appropriate healthcare and simulation training in adolescent communication as part of the junior doctor induction.
- Training has been addressed in the transition policy, and this policy highlights that administration staff also need to be involved, as providing a smooth transition is not all down to clinicians. This has had a positive impact locally.

Challenges

- There isn't a lot of training that exists, therefore if you want to deliver training you need to develop your own.

Recommendation

Ensure that all young people who may need to move from child into adult healthcare services can be identified as such on electronic patient systems, across all healthcare sectors.

Target audiences: NHS England, Digital Health and Care Wales and Northern Ireland Statistics and Research Agency with support from trust/health board executive committees and commissioners

Local examples of practice

- An alert for transition ("This patient is aged 14 years or above and is undergoing the process of transitioning into adult services") has been added to the electronic patient record, to allow staff to flag up patients aged 14+ who are moving from child to adult health services. This has been beneficial in terms of recording patient numbers, and in identifying patients moving into adult health services.

Recommendation

Ensure that transition from child into adult services is specified in the service outcome measures and that the financial support for this reflects the additional clinical and administrative time needed. Appropriate quality and outcome measures should be included in both child and adult service specifications.

Target audiences: Commissioners, Integrated Care Boards

Challenges

- Coding is the biggest barrier, as without this the complexity and size of the issue can't be understood.
- Complexity in understanding the different commissioning arrangements – money could be coming from joint commissioning arrangements, NHS England, Integrated Care Boards, and local authorities.

Additional resources

National Institute for Health and Care Excellence. 2023. Transition from children's to adult's services [QS140] https://www.nice.org.uk/guidance/qs140/resources/transition-from-childrens-to-adults-services-pdf-75545472790213

NCEPOD: The full report and supporting documentation can be downloaded from https://www.ncepod.org.uk/2023transition.html