The impact of transition on NHS diabetes service delivery: key audit results spanning 2003–2014

The first National Diabetes Transition Audit sheds light on processes and outcomes of care for young people with type 1 diabetes.

Steve Chaplin here examines the audit's key findings.

The transition between child and adult services has great importance for the quality of care provided during early adulthood. A lot can go wrong when young people leave the supportive environment of a paediatric service, where their parents have an integral role, to an environment where they are expected to exercise autonomy over their care.

Guidance and implementation

The risk is well recognised. Well over 10 years ago, the Department for Education and Skills and the Department of Health jointly published the first of several guidance documents on planning transition, backed up with models of transitional care and recommendations on planning and training.1 In 2012, the Children and Young People’s Health Outcomes Forum (a group of NHS, local authority and academic specialists convened by the Department of Health) reviewed how well the health outcomes that matter most for children and young people were being delivered by the public sector.2 It concluded: ‘Too many health outcomes for children and young people are poor, and for many this is involved with failures in care.’

That same year, NHS Diabetes published a review to identify best practice in transition care to form the basis of a work programme to improve outcomes.3 It defined transition as: ‘The period of time during which there is planned, purposeful and supported change in a young adult’s diabetes management from child orientated to adult orientated services, mirroring increasing independence and responsibility in other aspects of their life.’ Its key findings revealed a lack of confidence among clinicians that the plethora of guidance then available had been implemented (Box 1).

Nevertheless, the Care Quality Commission rated diabetes care as one of the better services in its cross-specialty review of NHS transition care, which otherwise too often uncovered disinterest and neglect in the quality of care offered to young people.4

NICE guidance

Seeking to raise standards throughout the NHS, the 2016 NICE guideline on transition services recommended a range of measures to improve planning, service user participation, support and accountability;5 a quality standard soon followed.6 This was very much about the transition process rather than outcomes – and with good reason. A systematic review of 43 studies of transition in diabetes care in Europe, North America and Australia found worse attendance after transition, difficulty with adult services and lead to increased attendance at clinics

The audit asked three questions:

• Is the transition from paediatric to adult care associated with changes in care process completion rates?
• Is the transition from paediatric to adult care associated with a change in treatment target achievements?
• Is the transition from paediatric to adult care associated with changes in episodes of diabetic ketoacidosis (DKA)?

The dataset

The age at transition is defined as the last audit year that a young person appears in the paediatric audit dataset; inclusion in the audit also required a record in the adult dataset for the following year. This yielded a population of 16 370 people, most of whom transitioned at age 18 or 19 (Figure 1). There were few records of people who transitioned in their early 20s. The data include no information about the transition care that people

Box 1. Key findings of NHS Diabetes’ transition review

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<th>Findings</th>
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<td>Effective transition processes are urgently needed</td>
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<td>Generally, professionals feel they do not do it well (or well enough)</td>
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<td>There is no clear model for what is most effective</td>
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<td>If done well, it is recognised this will help prevent complications and improve engagement with adult services and lead to increased attendance at clinics</td>
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<td>Young adults have repeatedly been surveyed and report they care more about the interaction with the health professional than the model of transition used</td>
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<td>There are many publications outlining why it is important, but more needs to be done on what health services actually need to do to implement a good transition service</td>
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| The transition from childhood to adulthood is particularly sensitive to disruption with both short- and long-term health effects... Transition will need collaborative support through medical, educational and psychological services, with crucial engagement needed between paediatric and young adult services to provide continuity of care, and give young adults confidence to continue to manage their diabetes... |

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The National Diabetes Transition Audit Audit results

The latest report from the National Diabetes Audit (NDA)8 is therefore timely. It is the NDA’s first report on transition and covers the period from 2003/04 to 2013/14, predating NICE guidance (but not many other publications that have sought to bring about change). Its preamble reinforces the importance of a good transition service for diabetes, stating:
received, whether it was planned or not, or whether they received continuous care. Importantly, the quality of diabetes care has improved during the period covered by the audit, so the overall statistics should not be compared with annual audit data.

**Care process completion rates**

NICE recommends that everyone with diabetes aged 12 or over should receive nine care processes of care (Box 2). Three of these (to assess renal function, obesity and smoking) were omitted from the audit due to inconsistencies in recording. Of the remaining six, the delivery of four is more prevalent among adults (Figure 2), with only glycaemic control being more frequent among children.

Completion rates tended to be higher in Wales than in England but the overall pattern was similar, as were pre- and post-transition differences. There were no striking differences between genders, by ethnicity (though the dataset included relatively few people from minority ethnic groups) or by social deprivation quintile. Longer duration of diabetes was associated with lower pre-transition and higher post-transition rates of care completion.

With increasing age at transition, pre-transition process completion rates remained flat or declined whereas post-transition rates increased. Least variation occurred between ages 16 and 19, suggesting that change before or after this period is associated with worse outcomes. However, this is also the period when most individuals transitioned and when a planned change is more likely.

**Treatment targets**

The target for glycaemic control for both adults and children is HbA1c ≤58mmol/mol (7.5%). Slightly more children than adults met this target (exact figures are not reported) but the proportion doing so fell after transition (from 15% to about 13% in England and from around 13% to 10% in Wales). There were no differences according to gender and ethnicity. Transition was not associated with change in the lowest two quintiles of social deprivation but the proportion achieving target HbA1c fell slightly for the others. Further, the pre-transition disparities between higher and lower quintiles persisted after transition. Age at transition did not affect target achievement, with pre-transition rates slightly higher for most ages. Clinicians will be aware that achievement rates for glycaemic control fall during the two to six years after diagnosis and then level off; this was not affected by transition.

The targets for blood pressure (i.e. <140/80mmHg), cholesterol (<4.0mmol/L) and renal function (different thresholds for age and gender; recording of these data has not been consistent nationally) were less frequently met after transition. The differences were usually small but most evident for cholesterol, for which achievement rates were lowest of the three (about 40% vs 80%). Transition had less effect on these figures in Wales than in England but there were no differences by gender, ethnicity or deprivation quintile. Similarly, there were no clear signs that age at transition influenced target achievement rates, which were generally lower with older age at transition for blood pressure and variable for cholesterol and renal function.

**Admissions for DKA**

Data for this outcome were filtered for admissions for which DKA was the primary or secondary diagnosis, for patients no older than 27, and for whom this was the final episode in a spell of care. Admissions occurring before or during the year of diagnosis, or three years before or after transition, were excluded. This left the period 2006/07 to 2011/12 for the audit; the total number of people included is not recorded.

There was not much to be deduced from analysing this outcome. DKA episodes increased after transition but that happens anyway with increasing time since diagnosis (Figure 3). The only lesson to be learned is that the greater risk of DKA with age should be taken into account when planning to meet the future needs of people with diabetes.

**Recommendations**

The NDA’s recommendations for improving the services can be summarised as ‘listen to what people are saying and act on it’. Clinical commissioning groups and local health boards ‘must understand that transition from paediatric to adult care is a vulnerable period’ and ‘should specifically contract paediatric and adult multidisciplinary...’
teams services to deliver appropriate, joined-up services during this period, so essential key healthcare checks are not missed and DKA admissions do not increase. For their part, specialist services should have clear transition pathways designed to make the process user-friendly but focused on sustaining stable HbA1c and minimising DKA.

The most concrete piece of advice is that ‘children and young people with type 1 diabetes remain in [paediatric services] until at least 16 years of age before transition. Adult Services should ensure that young people with diabetes have transitioned into their service by 19 years at the latest.’

Comment
This audit of about 10 years of NHS diabetes care has shown little or no impact from transition on service provision and clinical care, nor that the age of transition substantially affects outcomes in early adulthood. As other NDA reports have shown, deprivation is an unhealed wound, its effects persisting into adult care. Interventions in younger life are needed to address this.

The absence of a clear impact from what everyone agrees can be a difficult time is perhaps unsurprising. In the pre-NICE guidance era covered by this audit, there were probably many pathways with different levels and frequencies of intervention; the only factor common to all was the label ‘transition service’. The endpoints analysed here may not be the ones most clearly affected by transition (there is certainly a lack of consensus in published studies on what is). However, it is still important to measure and audit these endpoints because they are associated with outcomes in the longer term and it is at least reassuring that transition does not seem to be having a major effect. But, as guidance down the years has emphasised, the key to evaluating transition is to ask users what they want from a service and whether they are satisfied with it. This NDA report can only show – as it has in other reports – that some aspects of diabetes care are reasonably satisfactory and others are not for teenagers and young adults.

The value of the report for service providers and clinicians today is also somewhat limited by its datedness. Because NICE published its guideline two years after the cut-off date for the audit, the analysis shows what we want to improve on (which clinicians already know about) not whether the new direction of service provision is achieving anything.

The report’s recommendations are necessarily limited by the nature of the data analysed and lack the precision – some might say instructional nature – of the quality standard for transition. It specifies planning transition by age 13–14, an annual meeting with young people to review planning, a named worker to coordinate care and provide support, meeting a practitioner from adult services by transition, and follow up for young people who fall through the net. That leaves little doubt about what should be on the agenda for commissioners and providers alike.

Summary
The NDA report shows that transition has little measurable impact on the provision of services for young people with diabetes or their achievement of treatment targets.

It is reassuring that this potentially difficult period has not added to the many challenges now facing NHS diabetes services – at least, for those who engage with them. NICE
noted that: ‘Many young people with ongoing needs fall through the transition gap or disengage with services at this point. Their outcomes remain unknown and are a serious cause for concern. We need longitudinal studies on the consequences of poor or no transition and the costs of unmet need as a result of poor transition.’

5 Given the difficulties with treatment experienced by many young people with type 1 diabetes, this is an important goal for research. There is also much that is relevant to the impact of transition that the NDA cannot measure, such as user expectation and satisfaction, and for that we must rely on commissioners, providers and regulators to implement and police NICE guidance.

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References


