National Diabetes Transition Audit, 2011-2017

England and Wales

Prepared in collaboration with:

The Healthcare Quality Improvement Partnership (HQIP). The National Diabetes Audit (NDA) is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) which is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCAPOP Programme, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands.

NHS Digital is the new name for the Health and Social Care Information Centre. NHS Digital managed the publication of the 2011-2017 National Diabetes Transition Audit Report and also manage the National Diabetes Audit.

Diabetes UK is the largest organisation in the UK working for people with diabetes, funding research, campaigning and helping people live with the condition.

Royal College of Paediatrics and Child Health manage the National Paediatric Diabetes Audit and support the development and production of the National Diabetes Transition Audit (NDTA) report.

Why is Transition from Paediatric to Adult Care Important?

- Diabetes is a very difficult condition to manage. From the point of diagnosis onwards, diabetes has a major impact on the life of a young person, placing an enormous 24/7 burden on them and their family or carers. Supporting lifelong management of the condition is essential in achieving the most positive outcomes for the individual.
- Patients making the transition from childhood to adulthood are particularly at risk of disruption in care, with both short and long-term health effects. It is therefore very important that the handover of care from paediatric to adult services defends against this and does not intensify the risk.
- Transitional care needs collaborative support from medical, educational and psychological services. Engagement between paediatric and young adult services to provide continuity of care, and give young adults confidence to continue to manage their diabetes is pivotal. Falling short of this can lead to serious and lasting consequences, resulting in increased morbidity and mortality.

Introduction

- The National Diabetes Transition Audit (NDTA) links datasets from the adult and paediatric national diabetes audits. The NDTA has been designed to audit care provision during the period when young people with diabetes move from paediatric to adult based clinical care.
- A working group comprises the clinical leads and audit managers for both the National Diabetes Audit (NDA) and the National Paediatric Diabetes Audit (NPDA), analysts from NHS Digital, and representation from Diabetes UK. The working group has designed, developed and delivered the NDTA according to the requirements and methodology set out overleaf.
- The NDTA measures changes in glycaemic control and care provision across the period of transition. It signals priorities for improvement and provides a framework for monitoring the impact of improvement action plans.

Introduction

- This is the second published report for the NDTA. This report has linked data from the NPDA and NDA for the audit periods 2011-12 to 2016-17. The NDTA focusses on the large number of young people with Type 1 diabetes, with some information on the few with Type 2 diabetes.
- The first NDTA report can be found here: https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit/national-diabetes-transition-audit-2003-2014
- The report aims to answer the following audit questions:
  1. Is the transition from paediatric to adult care associated with changes in care process completion rates?
  2. Is the transition from paediatric to adult care associated with a change in treatment target achievements?
  3. Is the transition from paediatric to adult care associated with changes in rates of diabetic ketoacidosis (DKA)?

Key Findings

- It is of concern that, on average, young people with Type 1 diabetes experience deteriorations in annual care process completion, achievement of treatment targets and higher rates of DKA while transitioning from paediatric to adult services.

- However, this overall picture is the sum of considerable local service variation. Whereas most services demonstrate these adverse trends a large number show the opposite. This varies between measures, as is illustrated on slides 16, 21 and 26 of this report.

Recommendations

Clinical Commissioning Groups and Local Health Boards:

1. Look at how your local paediatric and adult services compare with the others in England and Wales. If required, support them to achieve improvements in the transition of young people from paediatric to adult diabetes services.

Specialist Services:

2. Adult and Paediatric Services
    i. Collaboratively compare yourselves to peer services.
    ii. Consider whether improvements may be accelerated through participation in the RCPCH and NDA Quality Improvement collaborative programmes.

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Identifying young people with continuous records through transition to adult care

Definition of “Transition”

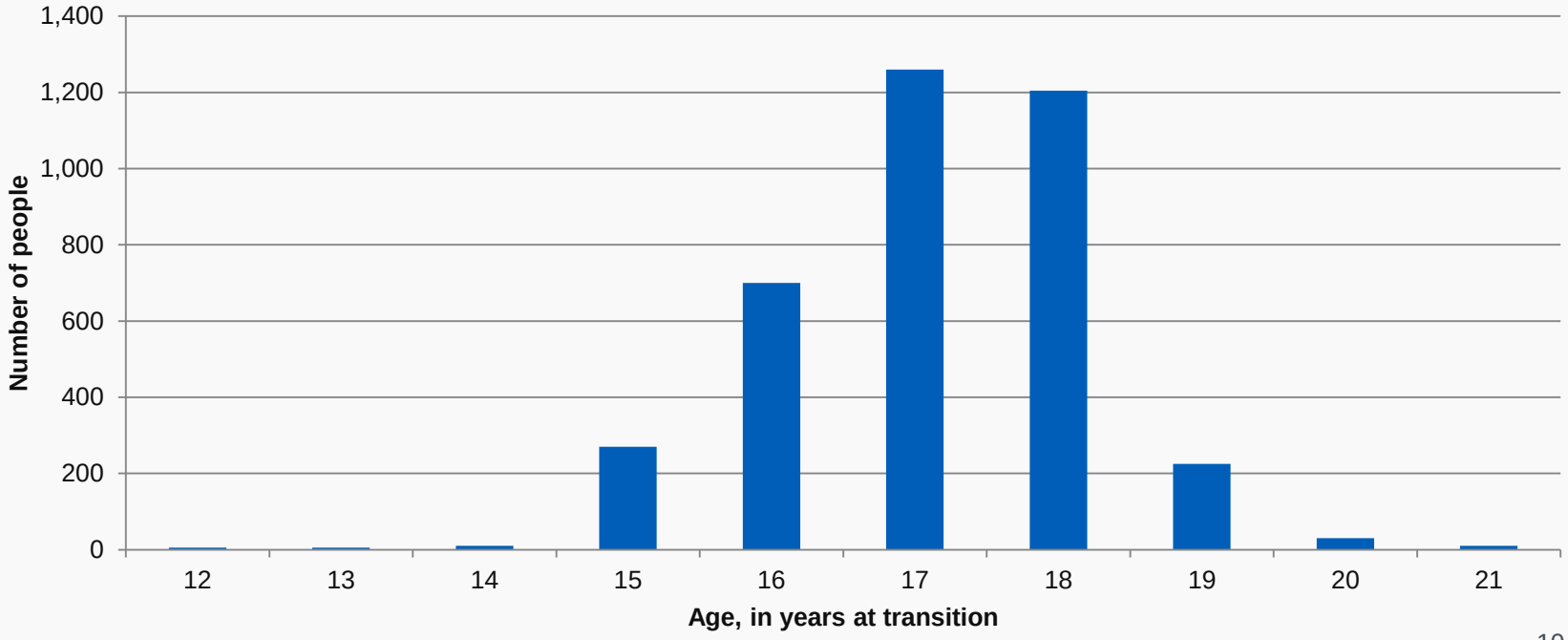
- The NDTA has linked data for the NPDA from 2011-12 to 2015-16 with NDA data from 2011-12 to 2016-17.
- Children and young people have been tracked from the NPDA dataset into the NDA dataset.
- This report uses the date of transition out of paediatric services as recorded by the NPDA (since 2011-12) to define the start of the transition to adult care.
- This differs from the definition used in the first NDTA report where the final year a patient appeared in the NPDA data was used to define their transition year. (Please see the methodology section of this report for further information.)
- Patients are included in the analysis only if they appear in the NDA in the following year. This is to ensure comparisons can be made to the NDA. Due to poor participation in some years of NDA, some people in NPDA have been excluded from the analysis.
  - 4,530 type 1 patients left paediatric care during the period, of which 3,800 were recorded in NDA the following year, leaving 730 excluded from analysis.
  - 155 type 2 patients left paediatric care, 120 were captured in NDA, with 30 excluded from analysis*.
  - 65 patients with an other or unknown diabetes type left paediatric care, with 30 recorded in NDA and 35 excluded from analysis.
- Although participation in NDA was poor in some years, in 2016-17 it was near complete at 95 per cent. 1,595 patients left paediatric care during 2015-16, of which 95 per cent (1510) were recorded in NDA in 2016-17. This suggests that there was little change in attendance at clinics on the transition from paediatric to adult care.

* *Totals may not sum due to rounding*

Age at Transition to Adult Care

- About 65 per cent of transitions occur at ages 17 and 18 years old.
- Over 25 per cent of people transition at ages 15 and 16.
- Over 5 per cent transition at age 19 to 20.

Figure 1: Age of transition of young people included in NDTA, Type 1 diabetes, 2011-2017, England and Wales



Analysis in this report

- Using the method described on page nine we were able to establish a transition cohort of 3,800 individuals with type 1 diabetes, and 120 with type 2 diabetes.
- As with the first NDTA report, this report focusses on people with type 1 diabetes. The small number of people with type 2 transitioning makes analysis of this cohort unreliable. Limited analysis of people with type 2 diabetes is in the supporting data tables accompanying this report, but this should be treated with extreme caution.
- For most measures in this report, performance is reported for the:
    - Year Before Transition – analysis of the NPDA for the audit year before transition.
    - Transition Year – analysis using combined NPDA and NDA data.
    - Post Transition Year – analysis of the NDA in the year following transition.
    - 2nd Year Post Transition – analysis of the NDA in the second year following transition.
    - 3rd Year Post Transition – analysis of the NDA in the third year following transition.

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What percentage of young people registered with Type 1 diabetes received the NICE key processes of diabetes care?

Care Processes

NICE recommends that all people with diabetes aged 12 years and over should receive each of the nine care processes[1,2,3] and attend a structured education program when diagnosed. **NPDA, however, does not include Serum Cholesterol and Serum Creatinine so this report is restricted to the remaining seven care processes.**

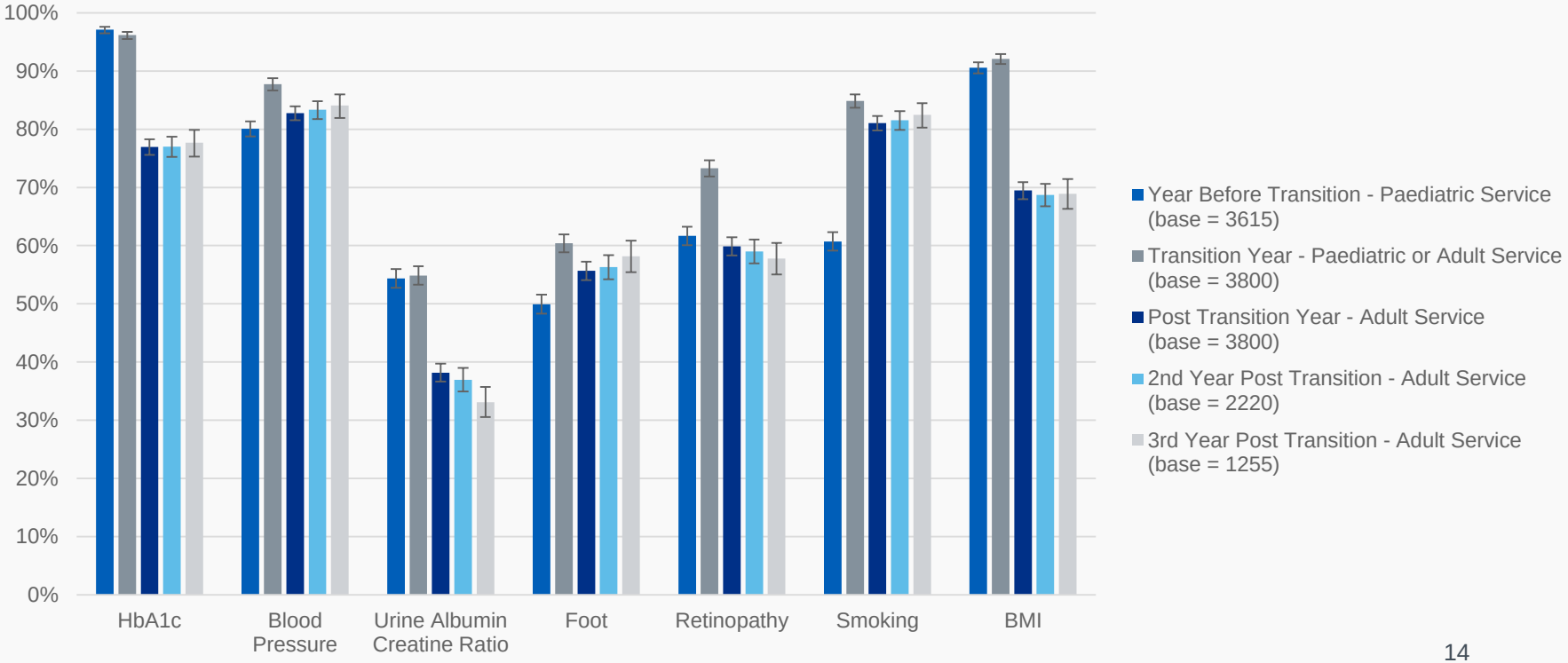
Nine Annual Care Processes for all people with diabetes aged 12 and over	
Responsibility of Diabetes Care providers (included in the NDA 8 Care Processes)	
1. HbA1c (blood test for glucose control)	**5. Urine Albumin/Creatinine Ratio** (urine test for kidney function)
2. Blood Pressure (measurement for cardiovascular risk)	**6. Foot Risk Surveillance** (foot examination for foot ulcer risk)
3. Serum Cholesterol *(blood test for cardiovascular risk)*	**7. Body Mass Index** (measurement for cardiovascular risk)
4. Serum Creatinine (blood test for kidney function)	**8. Smoking History** (question for cardiovascular risk)
Responsibility of NHS Diabetes Eye Screening (screening register drawn from practices)	
9. Digital Retinal Screening (photographic eye test for eye risk)	

1, 2, 3. Please see full list of footnotes in the definitions and footnote section.

Care Processes

- During the year of transition to adult care the completion rate of essential care processes were similar or better than the year before transition.
- Generally there was a 5 to 15 per cent reduction in completion of care processes in the 1st year following transition to adult care which did not improve in the 2nd or 3rd year.

Figure 2: Ratios of care process completion before and after transition to adult care, Type 1 diabetes, 2011-2017



Care Processes

- It is noted that delivery of care processes are financially incentivised in Paediatric diabetes services (via the paediatric diabetes best practice tariff) and in adult diabetes services that are delivered in primary care.

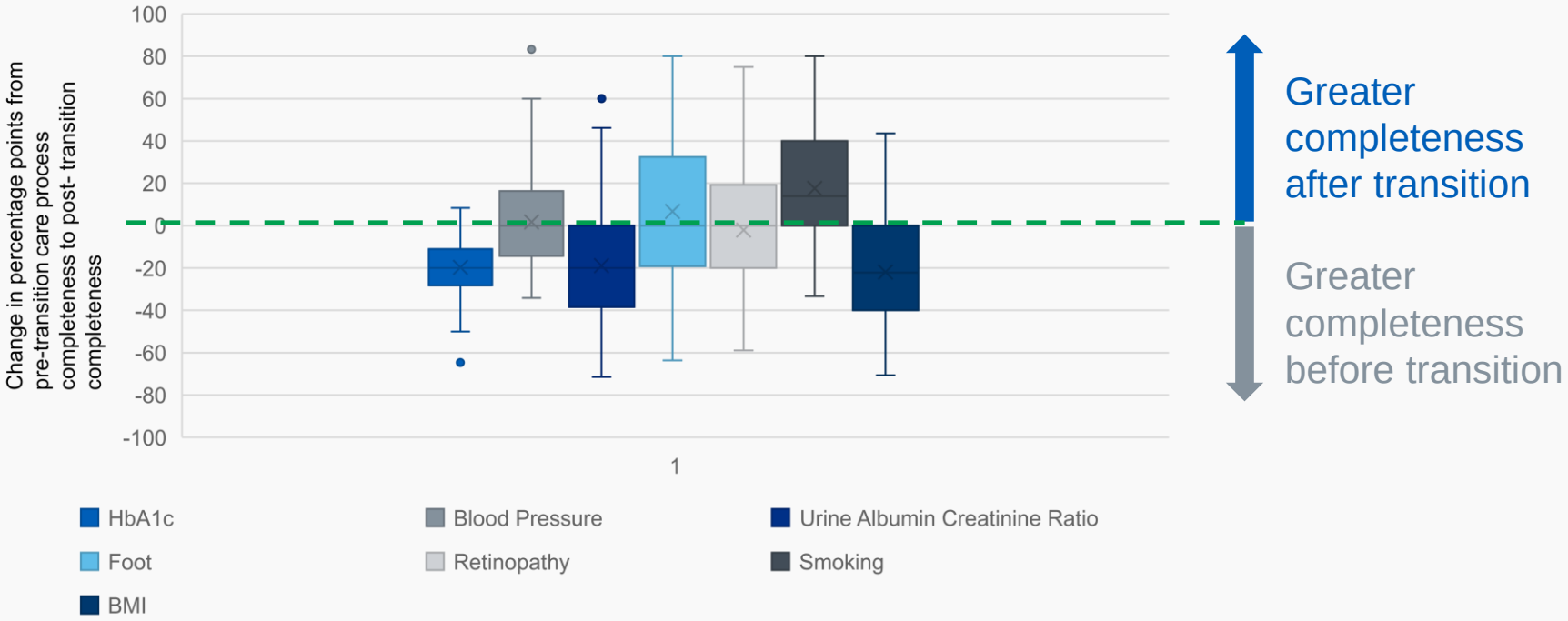
- Adult secondary care diabetes services are the only environment in which delivery of care processes are not financially incentivised, and poorer delivery post transition may well reflect this.

- However, the lack of financial incentives may result in poor recording, rather than poor delivery, of care processes, or may be a combination of both.

Care Processes – variation by unit/region

- The national averages conceal large variation at service level in the completion rates of care processes following transition from paediatric to adult care.

Figure 3: Variation, by Paediatric Unit*, in the Change of Care Process Achievement on Transition to Adult Care, Type 1 diabetes, 2011-17



*Only included in this figure are units with at least 18 patients transitioning during the period.
Difference in achievement between the Year Before Transition and the Year After Transition.

Care Processes – Comment

- In general, completion of care processes falls after transition from paediatric to adult services.
- Overall, during the year of transition care, care process completion rates either improved or stayed the same as that in the year pre-transition.
- There were, however, substantial differences between services; appreciable improvements during transition in some even though they were outnumbered by those with deteriorations in others.
- It is hoped that better understanding of the causes of this variation may help drive improvement. The NDTA Quality Improvement Collaborative, starting in early 2019, will support this.

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What percentage of young people registered with Type 1 diabetes were the NICE treatment targets for diabetes care achieved?

Treatment Target

- NICE recommends a treatment target of 48mmol/mol for HbA1c (glucose control) in young people with diabetes.

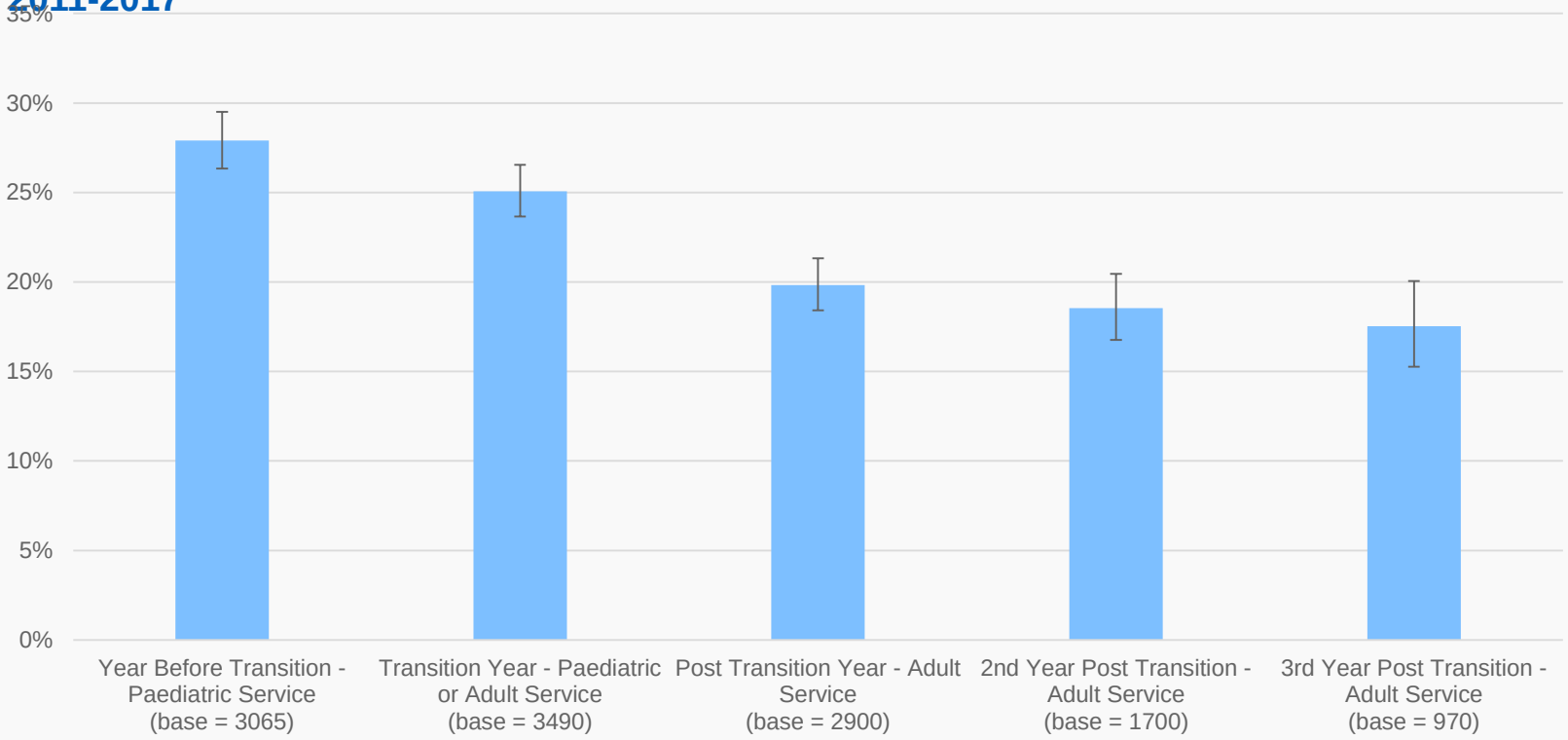
- Achieving target HbA1c reduces the risk of all diabetic complications.

- The NICE guidance changed in 2015 which was during the data period considered for this report. For the purposes of this report the target for HbA1c for adults and paediatrics is set as <=58 mmol/mol which was the NICE guidance before 2015.

Treatment Target

- Overall the percentage of young people achieving a target HbA1c of <=58mmol/mol fell post transition to adult care. 3 years after moving from paediatric to young adult services 10% fewer young people achieved this target.

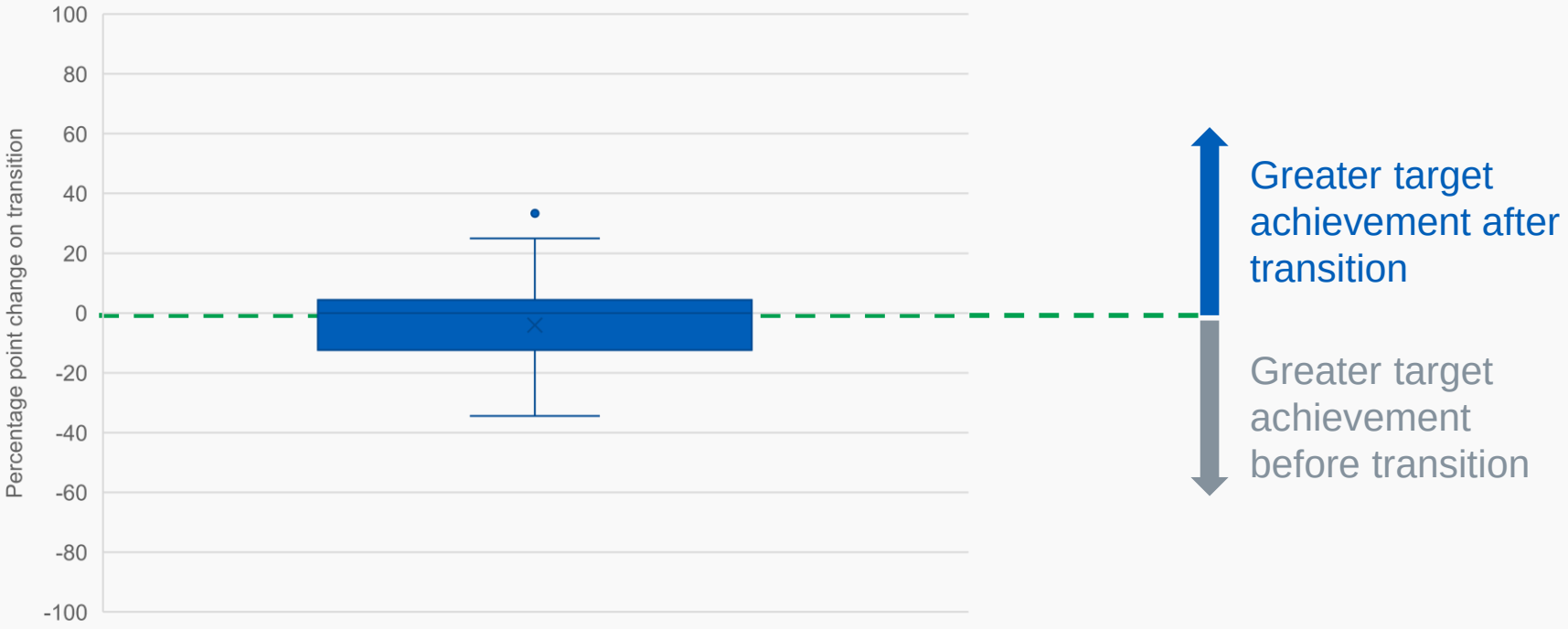
Figure 4: Proportions meeting HbA1c target pre- and post-transition to adult care, Type 1 diabetes, 2011-2017



Treatment Target – variation by unit

- Although the overall rate of HbA1c<=58mmol/mol target achievement is better pre transition to adult care, as for care processes, this is not universal. There is appreciable variability with some centres achieving better blood glucose control post transition.

Figure 5: Variation, by Paediatric Unit, in the change in HbA1c Treatment Target Achievement on Transition to Adult Care, Type 1 diabetes, 2011-17



*Only included in this figure are units with at least 18 patients transitioning during the period.
Difference in achievement between the Year Before Transition and the Year After Transition.

Treatment Target – Comment

- There is a need for Paediatric and Young Adult services to address the overall decline in target blood glucose control achievement rates post transition to adult care.

- But deterioration during transition is not universal.

- Better understanding of the causes of the variation may help drive improvement. The NDTA Quality Improvement Collaborative starting in early 2019 will support this.

- It is possible that important factors include:
  - Paediatric and adult services working together to ensure key messages are maintained during transition.
  - Maintaining engagement of young people during transition and onwards into adult life.

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How were cardiovascular risk factors managed in young people with type 1 diabetes during transition to adult care?

Risk Factors

Blood pressure and raised urinary albumin should be monitored as they identify people at increased risk of complications such as kidney and cardiovascular disease:

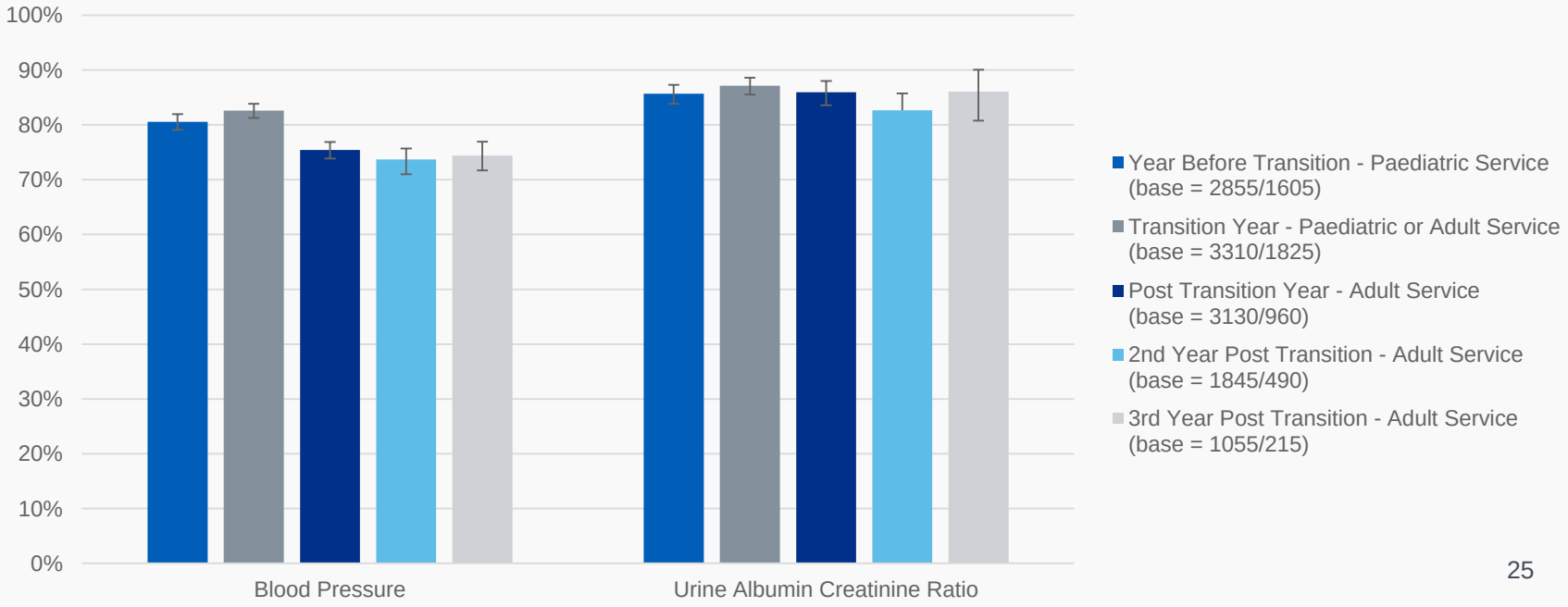
- Monitoring of blood pressure allows early detection of hypertension amenable to treatment that can reduce the risk of vascular complications and reduce the progression of eye disease and kidney failure.
  - The Blood pressure threshold for adult and paediatrics is defined as <140/80 mmHg

- Measuring Urine Albumin Creatinine Ratio (UACR) identifies people with increased risk of kidney and cardiovascular disease. Intensive glucose and blood pressure management can prevent progression.
  - The upper limit for UACR is 2.5mg/mmol in males and 3.5mg/mmol in females

Risk Factors

- There is a reduction in young people achieving target blood pressure post transition to adult care.
- There is little change in microalbuminuria rates post transition.
- The finding that ~20% of young people have blood pressure >140/80 pre transition is concerning.

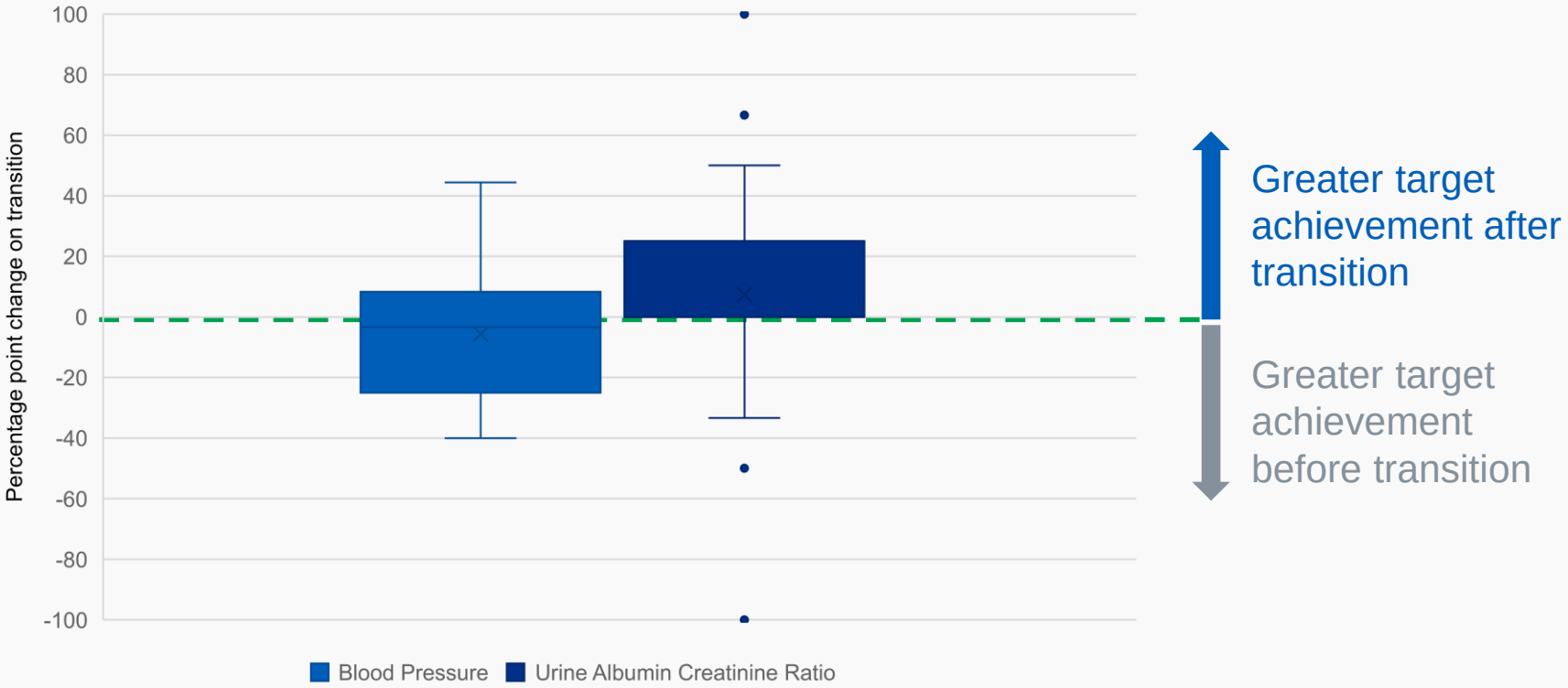
Figure 6: Ratios of thresholds met pre- & post-transition to adult care, Type 1 diabetes, 2011-2017



Risk Factors – variation by unit

- As for HbA1c, the national average represents the summation of very diverse local patterns

Figure 7: Variation, by Paediatric Unit*, in the Risk Factor Target Achievement on Transition to Adult Care



*Only included in this figure are units with at least 18 patients transitioning during the period.
Difference in achievement between the Year Before Transition and the Year After Transition.

Risk Factors – Comment

- The important risk factor, microalbuminuria (raised UACR) is present in over 10% of young people with Type 1 diabetes both before and after transition to adult care.

- Targeted efforts to control blood glucose and blood pressure can reduce this risk.

- NDTA does not currently measure type of insulin treatment or blood pressure interventions but it may going forward and meantime the poor overall post-transition rate of UACR check is a cause for concern.

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Diabetic ketoacidosis (DKA) Hospital Inpatient Admissions

DKA Hospital Inpatient Admissions

- Diabetic ketoacidosis (DKA) is a potentially life-threatening complication of predominantly Type 1 diabetes that occurs when insulin levels become very low.

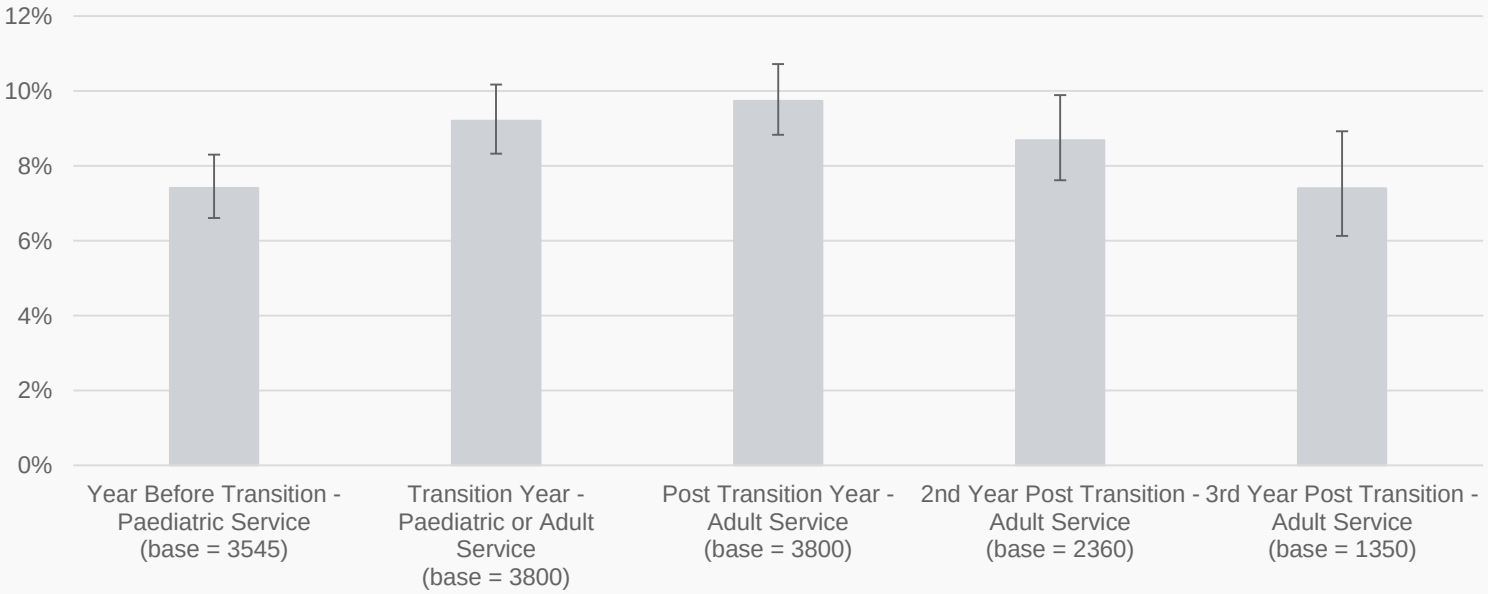
- As a result of the lack of insulin the body is unable to store or use blood sugar (glucose) which rises uncontrollably. Fat is broken down to use as an alternative energy source but in an uncontrolled fashion. This causes a build-up of potentially harmful, acidic, ketones.

- The high glucose and ketone levels lead to excessive urination, vomiting, dehydration, low blood pressure and collapse/coma. Without treatment DKA is fatal.

DKA Hospital Inpatient Admissions

- The year after transition to adult care (and the year of transition) more people admitted for DKA than during the year before transition.
- The DKA rates during the second and third year following transfer show no difference to the year before, during or after transfer.
- This highlights the vulnerability of the transition period.

Figure 8: Percentage of people admitted to hospital* with a diagnosis of DKA, Type 1 diabetes, 2011-2017



*Irrespective of the number of times admitted during the period.

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Insulin Pumps

People on Insulin Pump

- This section considers any difference in achievement of target glucose control between those people using an insulin pump in the transition year and those not.

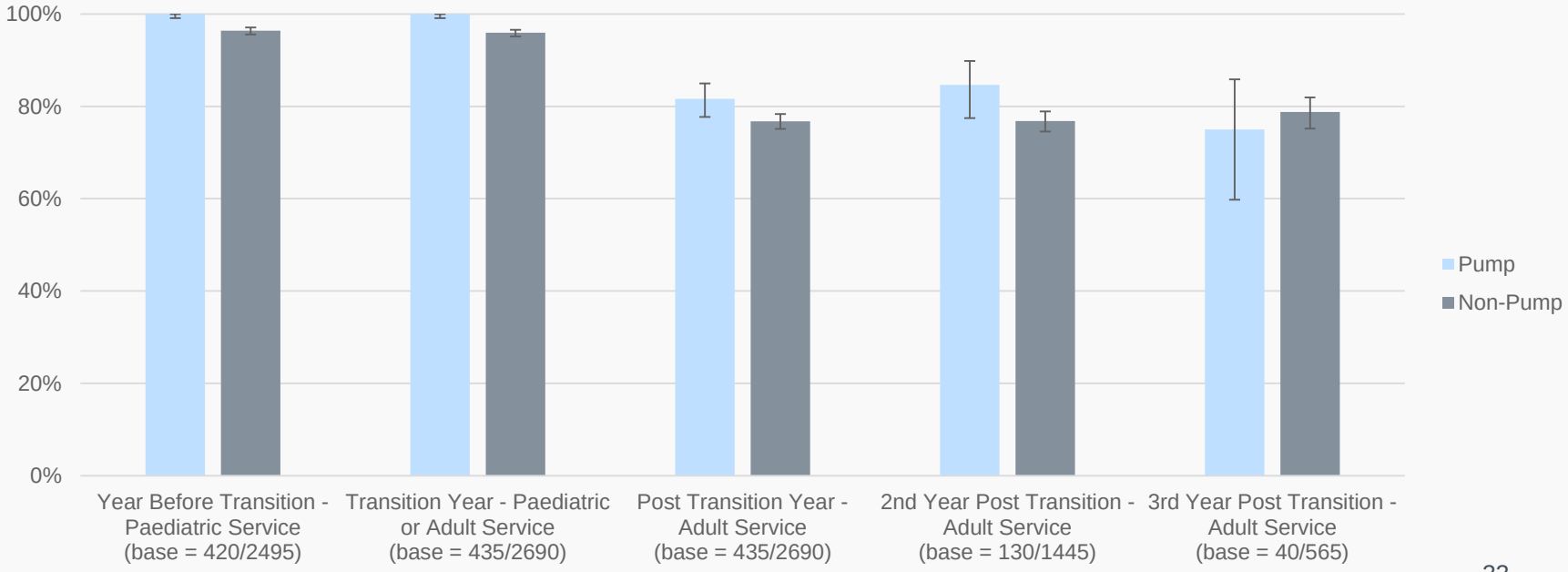
- A patient was defined as using an insulin pump during the transition year if they were recorded as doing so in the NPDA.

- 435 people, about 12 per cent, were identified as using an insulin pump in their transition year.

Insulin Pump – HbA1c Care Process

- The number of people using an insulin pump is relatively small.
- Care process completion before and during and after transition to adult care is higher for people on pump than not on pump.
- The years before and during transition see people on pump achieving a higher completion rate. Rates are not different after transfer.

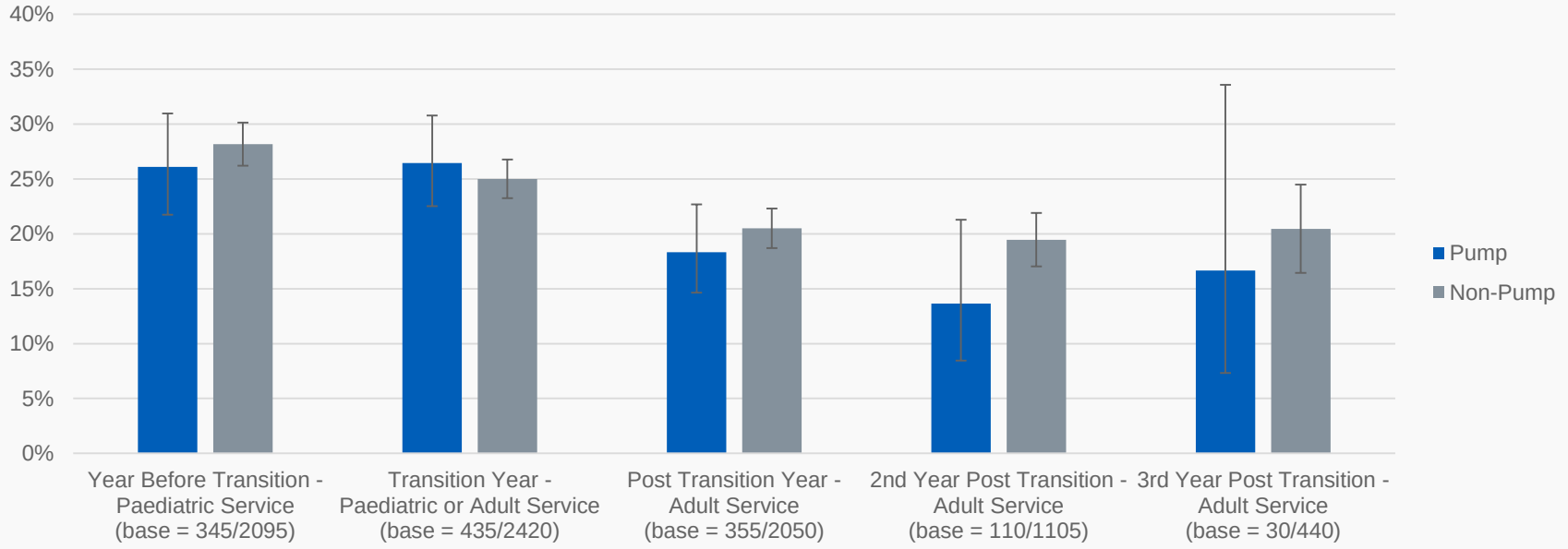
Figure 9: Proportions of all care processes met pre- and post-transition to adult care, by insulin pump use, 2011-2017



Insulin Pump – HbA1c Treatment Target

- Within each year, the HbA1c Treatment Target achievement is no different between those on pump and not on pump.
- The achievement between years is not discernibly different for people on insulin pump.
- Analysis is limited by the small numbers available.

Figure 10: Proportions achieving HbA1c target pre- and post-transition to adult care, by insulin pump use, 2011-2017



Methodology and data quality

Methodology – Time Period Covered

The National Paediatric Diabetes Audit (NPDA) years covered are 2011-12 to 2015-16.

- Audit year 2010-11 is included in the analysis to provide a pre-transition comparison for people who transitioned in 2011-12.

The National Diabetes Audit (NDA) years covered are 2011-12 to 2016-17.

- As 2016-17 was the latest NDA audit year available, the latest year of NPDA included for one-year follow-up is 2015-16, for two-year follow-up is 2014-15, and for three-year follow-up is 2013-14.
- This is why there is a decreasing sample size with increasing follow-up period.

Methodology – Time Period Covered

- For most measures in this report, performance is reported for the:
  - Year Before Transition – Analysis of the NPDA for the audit year before transition.
  - Transition Year – analysis using combined NPDA and NDA data.
  - Post Transition Year – analysis of the NDA in the year following transition.
  - 2nd Year Post Transition – analysis of the NDA in the second year following transition.
  - 3rd Year Post Transition – analysis of the NDA in the third year following transition.

- The data used spans over seven years of diabetes care. For both the NPDA and NDA, national figures for care process and treatment target achievements have improved over that time, therefore the results reported for overall care process and treatment target achievement may not reflect current national figures, and this should be borne in mind when comparing to recently published national reports.

Methodology - Definition of “Transition”

- Since 2011-12 the NPDA has recorded the date of transition out of paediatric services. This is the date used for this report. Patients are included in the analysis only if they appear in the NDA in the following year. This is to ensure there is something to compare with in the adult audit.
- Please note that this differs from the definition used in the first NDTA report.
- Some patients were recorded as having transitioned in more than one NPDA audit year. In these instances the latest date was used.
- Due to poor participation in some years of NDA, some people in NPDA have been excluded from the analysis.
  - 4,530 type 1 patients left paediatric care during the period, of which 3,800 were recorded in NDA the following year, leaving 730 excluded from analysis.
  - 155 type 2 patients left paediatric care, 120 were captured in NDA, with 30 excluded from analysis*.
  - 65 patients with an other or unknown diabetes type left paediatric care, with 30 recorded in NDA and 35 excluded from analysis.

* *Totals may not sum due to rounding*

Methodology – Previous Definition of “Transition”

- For the previous, and first, transition report, we used the point at which a person “disappeared” from the NPDA as a definition that they had transitioned, however it does not necessarily mean that they have undergone a planned transition move to adult services, but used as the best proxy that we had and defined the process of patients moving from paediatric to young adult based care.
- We did not know the exact date a person transitioned during the defined year that they moved out of paediatric care. Therefore, they may not have received a complete year of care prior to transition and care process rates may not have been complete.
- The more precise definition used this year provides more reassurance with regards to transition, but it is reassuring to note that many of the trends identified in the first report are mirrored in the more accurate data.

Methodology – Diabetes Type

- For a small number of people, the diabetes type recorded in NPDA was different to that recorded in NDA. For this report we have given preference to the NPDA recorded diabetes type. Where the diabetes type was recorded as ‘unknown’ in NPDA we have taken that recorded in NDA. This was for a small number of people.

- As with the first NDTA report, this report focusses on people with type 1 diabetes. This gives a cohort of 3,800 people.

- The small number of people with type 2 transitioning (120 people) makes analysis of this cohort unreliable.

Methodology – Biometric levels

Target: HbA1c

- Applied to both paediatric and adults:
  HbA1c values ≤ 7.5% (equivalent to 58 mmol/mol)

Risk Factor: Blood Pressure

- Blood pressure threshold for adults and paediatrics:
  Below 140/80 mmHg
  In children blood pressure is related to age and growth, however it is expected that all children have a blood pressure below this threshold.

Risk factor: Kidney

Kidney threshold for paediatric:

- *Albumin/creatinine ratio:*
  - Less than or equal to 2.5 mg/mmol (male)
  - Less than or equal to 3.5 mg/mmol (female)

Kidney thresholds for adult:

- *Albumin/creatinine ratio:*
  - Less than or equal to 2.5 mg/mmol (male) or 3.5 mg/mmol (female)
- *Albumin concentration:*
  - Less than or equal to 20mg/L
- *Albumin excretion (overnight):*
  - Less than or equal to 20µg/min
- *Albumin excretion (24 hours):*
  - Less than or equal to 30mg/24h

Methodology - DKA

DKA Hospital Inpatient Admissions.

Selected hospital inpatient data from the HES system was linked to the data on transition:

- Inpatient data was used from 2010-11 to 2017-18 (the final year of which was provisional data).

- The data from HES was filtered on:
  - Episodes with a diagnosis of DKA in any position.
  - Finished admission episodes of inpatient care.

Methodology – Insulin Pumps

- A patient was defined as using an insulin pump during the transition year if they were recorded as doing so in the NPDA.
- 435 people, about 12%, were identified as using an insulin pump in their transition year.
- Insulin pump data does not have full coverage in NDA over the years analysed in this report, and within the years it has been collected.

Methodology – Disclosure Control

- The standard NDA disclosure control method has been used for this report.

- All counts of people are rounded to the nearest 5, unless the number is 1 to 7, in which case it is rounded to ‘5’. Rounded numbers are used to calculate percentages. Median and centile calculations are not rounded.

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Definitions, footnotes, data sources and further reading

Definitions

Diabetes

Is a condition where the amount of glucose in the blood is too high because the pancreas doesn't produce enough insulin. Insulin is a hormone produced by the pancreas that allows glucose to be used as a body fuel and other nutrients to be used as building blocks. There are two main types of diabetes: Type 1 diabetes (no insulin); Type 2 diabetes (insufficient insulin).

Care Processes (NICE recommends all of these at least once a year)

Blood Pressure – a measurement of the force driving the blood through the arteries. Blood pressure readings contain two figures, e.g.130/80. The first is known as the systolic pressure which is produced when the heart contracts. The second is the diastolic pressure which is when the heart relaxes to refill with blood.
BMI measurement – Body Mass Index calculated from weight and height to classify under, normal and over-weight.
Serum creatinine – this blood test is used as measure kidney function.
Urinary albumin – this urine test detects the earliest stages of kidney disease.
Cholesterol – this blood test measures a type of fat that can damage blood vessels.
Foot check – this examination checks the blood supply and sensation (feeling) in the feet. Loss of either is an indicator of risk of foot disease.
Smoking Status – this records whether the person is a smoker. Smoking increases the diabetic risk for heart attacks and stroke.
HbA1c – this is a blood test of average blood glucose levels during the previous two to three months.

Definitions

Specialist Service

This is a service (often hospital based but sometimes delivered in a community setting) which includes diabetes specialists working in multidisciplinary teams. These teams usually comprise physicians (Diabetologists), Diabetes Specialist nurses and dieticians; it may also include clinical psychologists.

Treatment Targets (NICE defines target levels to reduce risks of complications for people with diabetes)

HbA1c - the closer this is to normal (less than 42mmol/mol) the lower is the risk of all long term complications of diabetes

Blood Pressure – high levels are a risk for heart attacks and strokes; they also drive progression of eye and kidney disease

Footnotes

1. See methodology and data quality section in this report for information regarding point of transition and DKA admissions

2. NICE recommended care processes http://www.nice.org.uk/guidance/conditions-and-diseases/diabetes-and-other-endocrinal--nutritional-and-metabolic-conditions/diabetes

3. National Service Framework (NSF) for Diabetes
   https://www.gov.uk/government/publications/national-service-framework-diabetes
   NICE Clinical Guidelines – GN17: Type 1 diabetes in adults: diagnosis and management
   http://www.nice.org.uk/guidance/ng17
   NICE Clinical Guidelines – NG28: Type 2 diabetes in adults: management
   http://www.nice.org.uk/guidance/ng28
   NICE – Diabetes in Adults Quality Standard http://guidance.nice.org.uk/QS6

4. NICE Clinical Guidance – NG18: Diabetes in children and young people
   https://www.nice.org.uk/guidance/indevelopment/gid-cgwaver118

Additional information

The following documents are available alongside this report,

- Supporting data in Excel
- Powerpoint version of this report
- Service level information for benchmarking and quality improvement purposes.

National Diabetes Transition Audit 2011-2017

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