# National Diabetes (Adult and Paediatric) Audit

## Meeting minutes part 1

**Wednesday 10 June 2016, Etc. Venues, 7 floor, 45 Moorfields, London EC2Y 9AE**

### Attendees

<table>
<thead>
<tr>
<th>Name</th>
<th>Position/Role</th>
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<tbody>
<tr>
<td>Jonathan Valabhji</td>
<td>chair, national clinical director for obesity and diabetes, NHS England</td>
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<td>Jackie Cornish</td>
<td>co-chair, national clinical director for children, young people and transition to adulthood, NHS England</td>
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<td>Cathy Hassell</td>
<td>deputy director, quality programmes, NHS England</td>
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<td>Matthew Fagg</td>
<td>deputy director, reducing premature mortality, NHS England</td>
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<td>Claire Lemer</td>
<td>associate national clinical director, children and young people, NHS England</td>
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<td>Richard Arnold</td>
<td>clinical programme lead, national medical directorate, NHS England</td>
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<td>Robert Grant</td>
<td>senior lecturer, health and social care statistics, NAGCAE</td>
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<td>David Cromwell</td>
<td>director, clinical effectiveness unit, Royal College of Surgeons of England</td>
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<td>Amanda Adler</td>
<td>consultant diabetologist, Addenbrookes Hospital</td>
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<td>Andrew Askey</td>
<td>lead GP, Walsall for Diabetes, St Johns Medical Centre</td>
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<td>Val Bailey</td>
<td>West Midlands Effectiveness &amp; Audit Network (MEAN), NQICAN</td>
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<td>John Barton</td>
<td>consultant endocrinologist, Bristol Royal Hospital for Children</td>
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<td>Leighton Coombs</td>
<td>senior programme analyst, NICE</td>
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<td>Anthony Davies</td>
<td>policy lead, Welsh Government</td>
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<td>Kate Fazakerley</td>
<td>patient representative (paediatric)</td>
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<td>Julian Hamilton-Shield</td>
<td>professor of diabetes and metabolic endocrinology, University of Bristol</td>
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<td>Mark Hannigan</td>
<td>programme manager, RCPCH</td>
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<td>Carol Jairam</td>
<td>diabetes specialist nurse, Imperial College Healthcare NHS Trust</td>
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<td>Nick Lewis-Barned</td>
<td>endocrinologist &amp; diabetes specialist physician, Northumbria Healthcare NHS Foundation Trust</td>
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<tr>
<td>Maureen McGinn</td>
<td>patient representative (adult)</td>
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<td>Ben McGough</td>
<td>DPP programme manage, Public Health England</td>
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<td>Carol Metcalfe</td>
<td>lead paediatric diabetes specialist nurse, Macclesfield District General Hospital</td>
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<td>Sean Newton</td>
<td>Welsh Government representative</td>
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Part 1 meeting: open discussion with stakeholders

Introduction and objectives of meeting

JV opened by setting out the strategic context of diabetes within England.

- Diabetes is one of 6 clinical priority areas for NHS England and broken into two large areas; diabetes treatment and care programme and the NHS diabetes prevention programme (DPP), called ‘Healthier You’. There is the intention for the DPP to link across to the audit eventually.

- The main areas of focus within the diabetes treatment and care programme are:
  1. achievement of treatment targets (3 for adults and 1 for children)
  2. empowerment and access to structured education
  3. inpatient care
  4. diabetic foot disease

- CCG improvement and assessment framework (CCG IAF) will focus on the first two of the above; structured education and treatment targets. One benefit of joining the two audits (paediatric and adult diabetes audits) would be to facilitate incorporation of children’s data for the CCG IAF.

- The Healthier You (DPP) programme would like to use the National Diabetes Audit to assess the success of this programme.
Data on young people who transition from paediatric into adult services is critically important to ensure continuity of support and management of their diabetes

**SH then set out the purpose and structure of the specification development (SDM) meeting**

- This meeting is part of the process of reprocurement for both the adult (NDA) and paediatric (NPDA) diabetes national clinical audits. Tenders will be launched in August 2016 and contracts awarded by February 2017.
- This SDM is a key element of the reprocurement process to ensure that the audits continue to address the key priorities and improvement questions in diabetes care, and continue to meet the needs of stakeholders.
- The SDM sets the scope and content for the audit(s). It is not a discussion to determine the mechanism by which the audit(s) will be delivered or to discuss individual providers.
- Audits are not just about collecting data. It is about using the data to drive local quality improvement and close the audit cycle loop.
- Attendees were asked to think about what a good diabetes audit would look like going forward over the next 3 to 5 years.
- The structure, format and objectives of the meeting were explained.

**Presentations were made by both the adult and paediatric audit clinical leads to provide an overview of the audit, including a brief background, challenges, and ideas for the future audits**

- **JW – Clinical Lead for NPDA presented on behalf of NPDA (presentation embedded)**
  - The audit collects data from paediatric units that provide services for children with diabetes, and they depend upon units to submit this data manually.
  - The NPDA collect data on any children up to the age of 24 that are looked after in a paediatric unit.
  - The following reports are produced by the NPDA:
    - Commissioners/clinicians national report
    - Lay report for patients and carers specifically
    - Unit level reports are also produced so providers can benchmark locally, regionally and nationally
    - PREMS report
  - Moving forward the NPDA team see collaboration with HSCIC and Diabetes UK (DUK) as a key element of the audit. NPDA also intends to produce clinical commissioning group (CCG) and local health board (LHB) reports in the near future.
BY – Clinical Lead for NDA presented on behalf of NDA (presentation embedded)

The NDA is built around providing measurement and data for adults with diabetes at every stage within their life. The NDA aims to support the myriad of organisations by providing them with measurements for improvement.

Moving forward the NDA team have clear ideas about how they could include more key elements of adult diabetes within the audit that are not currently recorded. They also see themselves working far more collaboratively with NPDA, other registries and national organisations.

Although NDA does not directly deliver improvement, the information it provides is essential as the impetus for facilitating ongoing change. NDA would like to fuel QI across the whole complex and multi-provider diabetes pathway.

Patient Involvement

SH presented the feedback from the patient engagement activities undertaken by HQIP to inform the SDM.

Patients are essential to include as a central part of developing a scope for the diabetes audits. Several methods of engagement were used to obtain patient feedback directly from patients – direct 1:1 conversations, email feedback, telephone focus groups. SH provided feedback on the main themes taken from patient feedback collected with the support of DUK. Patients would like:

1. more emotional and psychological support
2. better access to education for themselves, their carers and the healthcare professionals delivering their care
3. more integrated of services
4. access to better specialist dietary advice
5. to use the audit data to make decisions about their healthcare providers, and exercise their choice

KF, Carer Representative (paediatric)

KF was in agreement with all of the main themes presented. Adding that parents often have limited access to structured education depending upon the services they access. Parents commonly learn from other parents who have had access to better structured education (exposing variation in education provision). Parents also find their own information through reading books and looking online.

KF emphasised that parents need education to manage their children’s conditions but also need psychological support to motivate and guide them further.

MMc Patient Representative (adult)

MMc also recognised and agreed with all of the key themes presented.
Lack of integration of services was a particular issue that she had personal experience of and felt impacted upon adult diabetes self-management. The care that diabetes patients receive cuts across a number of clinical areas and the communication between services is lacking, with things like duplication of blood tests occurring.

Patient choice and access to information was also raised as a key factor by MMc. Patients could do more if they had more information and knowledge regarding their long term condition.

**Group discussion led by the Co-Chairs**

- JC confirmed that access to education and the variation of access across paediatric and adult services is large, and a real issue.

- From a PHE perspective a focus on prevention and early diagnosis is key. An approach across the care pathway is helpful for people with diabetes, from early diagnosis and prevention to management of the condition. Diabetes is part of ‘family’ of diseases around cardiovascular disease. NDA currently link with the National Cardiovascular Intelligence Network (NCVIN) but going forward strength through collaboration and linkage with other disease areas is needed to drive quality improvement.

- NDA and NPDA need to take every opportunity to present the data to the right audiences and groups to disseminate the audit data and key messages.

- It was noted that the future audit could be strengthened in it’s reporting of care processes for adolescents with Type 2 diabetes as they have particularly poor outcomes. Broadening the scope of the NPDA audit with Type 2 diabetes for adolescents would strengthen alignment of the adult and paediatric audit.

**Provider Participation (Primary Care)**

- JV commented that the delivery of diabetes care processes for type 2 Diabetes Mellitus (DM) is largely in primary care but participation has fallen lately.

- AA noted that GP participation is variable depending upon engagement. His particular area has good participation but there has been engagement and a quality improvement drive within the CCG area. Strong engagement of the audit with primary care providers and patients was encouraged.

- Participation in the audit from all sectors has been variable not just in primary care, but secondary and community care settings also. It was proposed that provider engagement with local community groups and patients can lever change when working in collaboration with the audits to drive QI.

- More could be done to engage people locally, specifically in areas where there are local diabetes groups that are not being utilised to drive QI.
It was noted that Quality Outcomes Framework (QOF) had incentivised primary care to submit performance data rather than have a focus on quality improvement.

The key to participation from primary care practices is good engagement, strong clear leadership and support with IG and IT. Within secondary care where there is managerial and clinical support and a good clinical audit department participation is better. The environment that supports primary care providers should be examined to establish how they could be better supported to engage.

Participation from primary care providers in Wales has been particularly good. The key to their success is the simplicity of taking part in the audit. They have one IT provider service that allows data to be pulled from the system with ease. There is very little work for the primary care services to do as there is little effort in the sign up and participation process. However it was noted that although participation is good additional engagement and effort is still needed to drive the subsequent quality improvement.

**Diabetes Prevention**

BM (PHE) delivered a short explanation of the NHS England diabetes prevention programme which has recently been commissioned. It is a community intervention delivered for individuals with ‘pre-diabetes’. Read codes have been developed for use in primary care to capture this information. It is proposed that the audit scope be broadened to capture the diabetes prevention programme.

AA supported a move towards including prevention within the scope of the audit.

There is a pilot within Newham (London) of a widening in the eligibility criteria for the diabetes prevention programme to include previous gestational diabetes.

Within Wales there is a slightly different approach. There is a combined programme for heart disease, stroke and diabetes, not just condition specific to diabetes. This community programme targets the most deprived.

There is scope for audit to stretch to include diabetes prevention within England and Wales. Starting earlier on the care pathway could broaden the scope to include prevention and not just disease management.

JWH suggested that it be worth including childhood obesity as part of prevention programme within type 2 diabetes mellitus prevention. It was felt that this would broaden the scope of the audits too far. Whilst the audits can carry out spotlight audits, there is a need to keep a tight focus on the core scope of the diabetes audits to ensure that only the pathway that can be measured is measure.

**Education and Dietetics**

SR commented that the audits could better capture the provision and uptake of education, capturing the types of education that are provided.
JV commented that while structured education as a whole is measured by the audits, there are no discrete parameters around this.

It was noted that there are structured education questions specifically within the PREMS (patient reported experience measures survey) element of the NPDA.

Dietetic input is often a feature of multidisciplinary MDT care for both adults and paediatrics care however the audits do not specifically measure the dietetics provision or the way in which it is measured.

KF remarked that there is too large of a variation in the provision of structured education.

Education was noted to have a direct impact upon behaviour change and therefore positive clinical outcomes. There was uncertainty of how education could effectively be captured and it was suggested that there may be a need to be more specific about what education actually means before measuring it.

CM noted that the new draft NICE Quality Standard for children with diabetes does now include standards for education and dietetics. These are awaiting publication.

It was felt that the audit should align to the new NICE guidance. JM noted that the new NICE Quality Standard for children includes not only a statement about structured education but also a statement about offering children and their carers/family members level 3 carbohydrate counting education.

Alignment allowing for comparison of education provision across both paediatric and adults audits would be beneficial. Comparing provision and which health care professionals deliver dietary information (e.g. nurses, dieticians, consultant) would be useful to capture.

**Care planning, patient experience and self care**

NLB highlighted the importance of patient involvement within care planning and the necessity of capturing if the express needs of patients are incorporated into the care planning process.

JV asked the group whether it was possible to expand the scope of the audit to include care planning and the elements of care they need to support their self-care?

AD felt that the audit could have a stronger focus on assessing the patient experience aspect of the care pathway.

A potential vehicle for capturing self care and care planning would be to use the patient experience of diabetes services (PEDS) module of the adult audit that was previously piloted.

RA explained that the commissioning of PREMS are not now routine within the (National clinical audit and patient outcomes programme (NCAPOP). They can be costly to develop and undertake and there is patchy evidence of effectiveness in driving quality improvement. It was suggested...
that this may be revisited but a cost-benefit exercise would be required to establish if this is worthwhile

- HR raised that the paediatric audit collects patient level data however dietetic input at an organisational level could provide a strong lever for quality improvement. Altering the scope to include an organisational audit combined with clinical data could be powerful in effecting change

- JV highlighted that in-patient, foot care and pregnancy modules of the adult audit already collect team level data combined with clinical patient level data

- BY noted that not all elements of the care pathway are collected at organisational level within NDA

**Diabetic Emergencies**

- CM noted that the current content of the paediatric audit does not clearly capture the number of children diagnosed with DKA and this needs to be included as it is a current clinical concern. Within her local CCG this is an issue and outcomes are poor. Audit data could support a local quality improvement campaign to improve outcomes

- JB highlighted the importance of early diagnosis for Type 1 diabetes mellitus (DM). The length of time to diagnosis could be examined through the primary care element of the NDA audit. Data could support campaigns around early diagnosis with an aim to reduce incidences of DKA in children with diabetes

- Stakeholders noted the importance of the NPDA retaining it’s identity as a paediatric audit so it does not lose this important focus. Whilst it would be beneficial to be able to examine the entire pathway, the data should still be broken down into specific paediatric and adults elements. Paediatric unit level info is very helpful and should not be lost

**Alignment between adult and paediatric audits**

- SH summarised that there was scope for better aligning the adult and pediatrics audits and that discussions so far had highlighted mutual need for data around education, dietary advice, self management and care planning and better alignment with national guidance

- Alignment of adult and paediatric audits and longitudinal data around the period of transition would be enormously helpful at preventing complications arising in adult care. This could support establishing whether the transition care currently being offered is acceptable

**Adult audit elements**

- JV asked if there are any other elements not yet included within the adult audit that should be part of a future audit

- A potential of linkage with the diabetic eye screening programme was raised. BY reported that this had been previously explored but the eye screening programme dataset lacked the capability to link with other datasets
o There is a lack of data to capture how patients are cared for when they transition between healthcare settings and providers. In particular diabetic women during pregnancy are managed by many healthcare providers, not just diabetic specialists

o AA highlighted that health inequalities are not adequately captured by the adult audit. In particular institutionalised patients such as those in nursing homes, jails and mental health settings are not included within the audit. She also noted that this is an audit, not a registry. The datasets should be rationalised whilst ensuring they capture enough information to inform confounders and risk adjustment

o The audit cannot grow exponentially and without limit. There is a need for a tight core set of data that can also be used longitudinally. However, there is the flexibility to do spotlight audits on additional datasets on a rolling basis. It is important to recognise that the audit cannot collect data on everything

o A spotlight PREM run every other year to allow for improvements to be made each time a report is released was suggested

o MMc suggested that an organisational audit comparing provision of insulin pumps and some further detail around this would be helpful for patients. Continuous glucose monitoring is not currently included within the pump audit

Parity of Esteem and Psychological Support

o There is a need to address parity of esteem for people who have co-existing mental and physical health problems. There is potential to include mental health settings and teams within the diabetes audit

o A challenge for patients is that their diabetes control is largely monitored through HBA1C levels and the guidance and information available on this is complex. The emotional and psychological aspect of diabetes support is important because patients can struggle to manage their HBA1c. However the availability and provision of psychological and emotional support can be difficult to measure and for that reason there is less of a focus on this aspect within the audit

o KF highlighted that good psychological support results in better management of HBA1C levels and would therefore result in less clinical resource needed

o Patients recorded on the primary care learning disability register are included in the current round of the adult core audit and it was suggested that the same method and logic could be used to record patients with co-existing mental health diagnoses to capture data on their diabetes care

o The audit should capture inequalities in access to care and diabetes technology
**Quality Improvement and Engagement**

- The importance of engagement as a means to driving quality improvement was highlighted. The intelligence networks deliver masterclasses in partnership with some of the audits to maintain stakeholder engagement, disseminate audit data and provide support in interpreting the data.

- RG noted that timeliness of access to data and reporting was important in supporting local quality improvement. Layering of detail, so that information is presented in different ways for different stakeholders, within the reports would be helpful so that clinicians, parents/carers and patients can all absorb the relevant information. There is a need to turn the data round as quickly as possible to make it real and current for QI to take place.

- Patient experience measures are a driver to quality improvements. If any particular elements come out of the PREMs then there was a wish among stakeholders to build these elements into a future NPDA audit.

- HQIP commissioners should ensure that the audit scope is very specific around the requirement to engage with local networks, CCGs and LHBs.

- NHS England and national levers could encourage local providers to engage with the audit and take responsibility for quality improvement.

- **JV summarised:**
  - A strong focus should remain on paediatric and adult components of diabetes care, even if the decision is made to combine both audits. It would be both interesting and of use to view the entire pathway from paediatric to adult services, but the data should still be broken into specific paediatric and adult elements.
  - There is an overlap around data collection by both adult and paediatric audits in the following areas:
    - Education
    - Dietary advice
    - Alignment with professional standards
    - Psychological support
    - Quality of transition
    - Self management and care planning
    - Translation of audit data into sustained improvement.
  - Stakeholders gave a strong steer for measures of patient experience of care to be included within the audit(s) moving forward.
  - Including patients with diabetes who also have co-occurring mental health issues should also be considered for inclusion within the audit(s).
There were mixed messages amongst the group as to whether the audits should be combined into one or remain separate. There was, however, a clear consensus that both audits should be aligned and work collaboratively.

JV thanked the group for their contributions and part 1 of the meeting closed.