The impact of new NICE guidance on pre-conception care in Birmingham

Jackie Webb

The recent NICE Diabetes in Pregnancy (2008) guidance has bought pre-conception care into the domain of primary care. Prior to this the CEMACH reports of 2005 and 2007 had identified a worrying lack of pre-conception care within secondary and primary care. To this day outcomes remain poor despite the assertions of Standard 9 of the National Service Framework (Department of Health, 2001) and the 1989 St Vincents Declaration. In this article, the author aims to explore how the NICE guidance fits within integrated care. She identifies the challenges faced by primary care and gives an insight into pre-conception care from a secondary care perspective.

The St Vincents Declaration of 1989 identified the need to improve pregnancy outcomes for women with pre-existing diabetes so that they mirror those achieved in the population without diabetes. Since then, no real progress has been made. This is despite Standard 9 of the National Service Framework which challenged the NHS to 'develop, implement & monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy, to optimise the outcomes of their pregnancy' (DoH, 2001). It can be suggested that as the framework was launched without 'ring-fenced funds' that this is not surprising. Not only does it take drive and vision to change services but in the ensuing years there have been so many changes in the NHS that it is difficult to retain a focus which is not fiscally driven.

Three years later, in 2005 the CEMACH enquiry identified that 'women with diabetes are [still] poorly prepared for pregnancy'. In 2007 CEMACH reported statistics such as 'only 17% of units in England, Wales & Northern Ireland offered structured multidisciplinary pre-conception care' and 'two thirds of women had sub optimal pre-conception care'; thus ensuring the drive to improve services for this group of people was re-focussed.

In December 2005 the NICE diabetes in pregnancy guideline development process began, the author felt fortunate to be a part of the guideline development group and can attest to the robust and methodical systems and processes employed in developing NICE

Article points

1. The St Vincents Declaration of 1989 identified the need to improve pregnancy outcomes for women with pre-existing diabetes so that they mirror those achieved in the non-diabetic population. Since then, no real progress has been made.
2. The NICE Diabetes in Pregnancy guidance spans the period from pre-conception to post birth and as with all NICE guidance is thoroughly evidence based and will not disappoint those who enjoy controversy.
3. NICE has recognised that pregnancy planning in women with pre-existing diabetes is one of the most important aspects of their care.

Key words

- Pre-conception care
- Gestational diabetes
- NICE guidance
- Pre-conception clinic

Jackie Webb is a Diabetes Specialist Nurse Manager at the Heart of England Foundation Trust, Birmingham.

Page points

1. In the wake of the recent NICE guidance, early pre-conception care now sits firmly within the remit of primary care.
2. In our locality most people with type 1 diabetes are managed in secondary care for at least the first 2 years following diagnosis while those with type 2 or a previous diagnosis of gestational diabetes are managed by the primary care team.
3. Women with pre-existing diabetes of child-bearing age are not always encouraged to verbalise their desires to conceive; therefore, a clinic appointment is often a missed opportunity to raise the issue of pregnancy and confirm that the woman is aware of the need to access pre-conception care (Webb, 2006).
4. Therefore, NICE (2008) suggests that starting from adolescence, at each contact with the patient, healthcare professionals within the primary care team will need to document the woman's intention regarding pregnancy and contraception use.

guidance. The resulting NICE diabetes in pregnancy guidance spans the period from pre-conception to post birth and, as with all NICE guidance, is thoroughly evidence based and will not disappoint those who enjoy controversy.

Impact on primary care

The general trend over the last 25 years in the UK has been of falling fertility at younger ages alongside rising fertility at older ages (Dunnell, 2007). This has led to a steady increase in the mean age of childbearing which has implications in women with pre-existing diabetes. Such women may have developed diabetes some years ago and therefore, are possibly at a greater risk of having already developed complications to their condition prior to planning a pregnancy.

Notwithstanding this, in the wake of the recent NICE guidance, early pre-conception care now sits firmly within the remit of primary care. Given the shift of diabetes care management from secondary care based clinics to a more integrated service delivered in primary care, the onus is now on GPs and practice nurses to deliver first-line pre-conception care.

Integrated care pathways as detailed in the government white paper *Our Health, Our Care, Our Say* (DoH, 2006) were designed as tools to incorporate and deliver national guidelines. The Department of Health defines integrated care as 'when both health and social care services work together to ensure individuals get the right treatment and care that they need' (DoH, 2006). The tripartite nature of an integrated care pathway – personalisation, efficiency and effectiveness – is uniquely placed to reshape services around the individual, reduce unnecessary variations, manage clinical risk and meet the requirements of clinical governance. These care pathways should improve navigation between services thereby addressing some of the inequalities in access experienced by ethnic minority groups. The existence and use of such integrated care pathways should now allow transition between primary and secondary care to be more fluid and less of a 'nightmare' for the patient.

Most care providers and integrated clinical networks have (over the last few years at least) developed referral pathways for all aspects of chronic disease management. In our locality most people with type 1 diabetes are managed in secondary care for at least the first 2 years following diagnosis while those with type 2 or a previous diagnosis of gestational diabetes are managed by the primary care team. Thus it follows that the majority of women with pre-existing diabetes will be managed by their primary care teams who are uniquely placed to offer multidisciplinary care such as smoking cessation, the management of teratogenic drugs, dietary advice, folic acid supplementation, contraception planning and structured education.

Improving awareness of need

Women with pre-existing diabetes of child-bearing age are not always encouraged to verbalise their desires to conceive; therefore, a clinic appointment is often a missed opportunity to raise the issue of pregnancy and confirm that the woman is aware of the need to access pre-conception care (Webb, 2006). Even when this is not the case, the author feels that previously there was insufficient emphasis placed on the need to give pre-conception care at the appropriate time.

Other factors which undoubtedly impact on the uptake of pre-conception care services relate to the women's ability or understanding of the need to access health care including communication-based and cultural barriers to understanding, as well as the physical difficulty of accessing a secondary care service (Williams and Riley, 2006).

NICE pre-conception care guidance

NICE has recognised that pregnancy planning in women with pre-existing diabetes is one of the most important aspects of their care. Previously (and in the authors experience) there has been little recognition of this fact which has resulted in women with pre-existing diabetes conceiving with sub-optimal glycaemic control, and in most, while taking what are viewed as teratogenic medications such as statins. Therefore, NICE (2008) suggests that starting from adolescence, at each contact with

the patient, healthcare professionals within the primary care team will need to document the woman's intention regarding pregnancy and contraception use. They will need to discuss the importance of planned pregnancies and give advice and information about the benefits of optimal glycaemic control in the pre-conception period. NICE (2008) suggest that at this stage this intervention should form part of and build on the woman's routine care. However, in the author's opinion, there will be a need for a dedicated clinic once the woman has verbalised a desire to plan for pregnancy.

One of the most important pieces of advice that this guideline gives is that women with pre-existing diabetes who have individualised targets with an HbA_{1c} greater than 10% should be advised to avoid pregnancy (NICE, 2008).

Prior to this NICE guidance the author was constantly aware that the advice and information being given at a woman's first appointment in a secondary care based pre-conception clinic often had a negative impact as so much information relating to the potential harmful effects of poor glycaemic control, teratogenic medication, risk of complications and probable caesarean section had to be provided, that it was almost impossible for the woman and her family to visualise a non-medicalised pregnancy. Women often left the clinic wondering 'if it was all worth it', and fearful of potential outcomes. In the author's experience the amount of information given is daunting – even frightening – for women and their family.

Implementing the recent NICE guidance should prevent this, as advice and general information will be given at a significantly earlier stage and in some cases at diagnosis of diabetes. The need for planning, the reason for targets, changing medication and optimising control will hopefully be driven by the woman who will be more empowered to self-manage her diabetes and able to identify the timing and place of the intervention she needs.

This guideline formalises care and sets out the level of information that needs to be provided by healthcare professionals to give women the best chance of having a healthy pregnancy as detailed in the NICE user reference guide (NICE, 2008).

Our Pre-conception clinic

The pre-conception clinic at Heartlands Hospital, Birmingham, is part of the Heart of England Foundation Trust and was set up in 2002. It is a nurse-led clinic which currently operates from Heartlands Hospital twice a month. There is a clinic at Good Hope hospital with whom Heart of England merged in 2007 however this article will focus on the service offered at Heartlands Hospital.

From data collected at the hospital it was identified that in 2005 less than 5% of referrals were received from primary care, in 2007 this figure was 30%, with the remaining referrals coming from secondary care based diabetes clinic, maternity and women self-referring.

Evidently many girls and women of child-bearing age with pre-existing diabetes were not receiving the care and information they needed pre-conceptually and there was no evidence to suggest that this was being provided by their primary care team. Although the number of referrals from primary care had increased it does not represent the number of women presenting pregnant with little or no advice.

In 2007 the combined number of births at Heartlands and Solihull hospitals was 7500; over 500 of these were complicated by diabetes and of this number, 470 (94%) were from an ethnic minority background. The diabetes team receives between 8 and 15 referrals per week of women with gestational diabetes. Our secondary care based antenatal diabetes clinics regularly see 50 women at Heartlands and 20 women at Solihull each week in the multidisciplinary antenatal diabetes clinics.

Our diabetes specialist midwife has an average caseload of 100 women. Currently this breaks down to 5 women with type 1 diabetes, 11 with type 2 and 84 with gestational diabetes of whom 50% have been transferred to insulin therapy.

In a year there are approximately 1000 patient interventions and in 2007 insulin therapy was initiated in 276 women (gestational and type 2 diabetes).

All newly referred women are invited to attend their first appointment with their partner. Their initial appointment is for 1 hour due to the

Page points

1. Prior to this NICE guidance the author was constantly aware that the advice and information being given at a woman's first appointment in a secondary care based pre-conception clinic often had a negative impact as so much information relating to the potential harmful effects of poor glycaemic control, teratogenic medication, risk of complications and probable caesarean section had to be provided, that it was almost impossible for the woman and her family to visualise a non-medicalised pregnancy.
2. Implementing the recent NICE guidance should prevent this, as advice and general information will be given at a significantly earlier stage and in some cases at diagnosis.
3. This guideline formalises care and sets out the level of information that needs to be provided by Healthcare professionals to give women the best chance of having a healthy pregnancy.
4. All newly referred women are invited to attend their first appointment with their partner. Their initial appointment is for 1 hour due to the amount of information which needs to be given and received.

Box 1. Changes we need to make to heed NICE guidance.

- Improve indivualised targets
- Explicit advice to avoid pregnancy if HbA_{1c} >10%
- Metformin use
- Folic Acid
- Tighten up procedures and advice
- Ketone testing
- Structured education
- Monthly HbA_{1c}

amount of information which needs to be given and received. Measures are being taken to make this first intervention more concise; however, it is important that this is not to the detriment of the overall content of the session.

Specifically, advice and information is given relating to the issues that are felt to be of greatest importance: the risks associated with parental consanguinity, which has been linked to congenital abnormalities (eg Richards, 1967); the need for 5mg folic acid daily; glycaemic control targets (HbA_{1c}<6.1%) are discussed as is the increased risk of hypoglycaemia associated with treatment intensification (DCCT Research Group, 1996). Further, it is emphasised that maintaining tight glycaemic control pre-conception and during pregnancy is very hard work and the woman needs the support and encouragement of her partner and other family members during the pre-conception period and throughout pregnancy.

Women with diabetes and their partners are invited to see a dietitian, who assesses diet and provides education and advice relating to foods which need to be avoided during the pre-conception and pregnancy period; they receive retinal screening with mydriasis if this has not been conducted in the previous 6 months.

Women with diabetes were reviewed every 2 months in the follow-up clinic with telephone intervention in between; however, the recent NICE guidance states that monthly HbA_{1c} needs to be performed which will have an impact on the service we currently offer and we have yet to establish how this will be managed.

Once baseline blood, urine and eye screening results are available, women with diabetes are informed of these results, as is the GP (in a standard letter format which allows us to request the GP changes or adds to treatment where necessary). This procedure is replicated when women attend subsequent follow-up appointments.

For the majority of women following their initial clinic visit, in order to intensify treatment and improve control, women with diabetes have had their treatment regimen altered in an effort to optimise control. In many cases this has necessitated initiation of insulin therapy. However, given that most women will now receive pre-conception information and advice from their GP it is anticipated that referrals to our secondary care based clinic will decline (See *Box 1* for changes we need to make to heed NICE guidance).

This will give us the opportunity to review and perhaps be more creative with developing our services and therefore the recent NICE guidance is viewed as an opportunity rather than a threat. ■

Acknowledgements

This article was undertaken by a member of the guideline development group on behalf of the National Collaborating Centre for Women's and Children's Health which received funding from the National Institute for Health and Clinical Excellence. The views expressed in this publication are those of the author and not necessarily those of the Institute.

Confidential Enquiry into Maternal and Child Health (2007) *Diabetes in pregnancy: are we providing the best care? Findings of a national enquiry: England, Wales and Northern Ireland*. CEMACH, London

Confidential Enquiry into Maternal and Child Health (2007) *Saving mothers' lives: reviewing maternal deaths to make motherhood safer—2003-2005*. CEMACH, London

Department of Health (DoH; 2001) *National Service Framework for Diabetes: Standards*. DoH, London

Department of Health (DoH; 2006) *Our Health, Our Care, Our Say* DoH, London

Diabetes Control and Complications Trial Research Group (DCCT; 1996) Pregnancy Outcomes in the Diabetes Control and Complications Trial. *American Journal of Obstetrics and Gynaecology* **174**: 1343–53

Dunnell K (2007) *The changing demographic picture of the UK National Statisticians Annual Article on the Population*. National Statistics, London. Available at: http://www.statistics.gov.uk/articles/population_trends/changing_demographic_picture.pdf (accessed 11.06.08)

National Institute for Health and Clinical Excellence (NICE; 2008) *Diabetes in Pregnancy: management of diabetes and its complications from pre-conception to the post natal period*. NICE, London. Available at: www.nice.org.uk/CG063 (accessed 11.06.08)

Richards BW (1967) Down's Syndrome and parental consanguity. *Developmental Medicine and Child Neurology* **9**: 351–2

Webb J (2006) Pre-Conception Care: Bridging the Gap *Journal of Diabetes Nursing* **10**: 140–4

Williams R, Riley P (2006) The year of the disadvantaged and the vunerable. *Diabetes Voice* **51**: 30–3