# Pre-conception care: Bridging the gap

# Jackie Webb

# Article points

- 1. Although the need to improve outcomes of pregnant women with pre-existing diabetes has been highlighted, there are shortcomings in meeting this need.
- 2. Poor uptake of preconception care is a factor involved in this.
- Communication-based and cultural barriers to understanding the need play a role in poor uptake.
- 4. The author describes the efforts of her team to try to improve attendance at a pre-conception clinic for women with diabetes.

## Key words

- Pregnancy
- Pre-conception clinics
- Uptake of care

Since the St Vincent Declaration of 1989 (http://pcdeurope.org/view/6 [accessed 18.04.2006]) there has been a challenge to improve the outcomes of pregnant women with pre-existing diabetes. This challenge was replicated in Standard 9 of the National Service Framework for diabetes (Department of Health, 2001). However, the recent report from the Confidential Enquiry into Maternal and Child Health (2005) has identified that in the West Midlands healthcare professionals are failing to improve the outcomes. This article explores the continuing challenges experienced by a diabetes team in attempting to improve the uptake of pre-conception care, thereby enabling progress towards achieving the desired, stated and necessary outcomes.

he area which the Heart of England NHS Foundation Trust serves is in the main covered by two primary care trusts (PCTs): Eastern Birmingham PCT and Solihull PCT. These PCTs have markedly different patient populations and prevalences of diabetes.

Eastern Birmingham PCT covers a population of 251 000 divided among 10 wards, nine of which fall within the top 20% of the most deprived wards in the country. The PCT is served by 59 practices; however, 53% of these are single-handed practices. All of the wards covered are classified as urban and among the 25% least healthy in England (Eastern Birmingham PCT, 2006). Non-White people mainly South Asian people - make up 97% of the population. The prevalence of diabetes is 4.1%, whereas the national figure is 3.3% (Health and Social Care Information Centre [HSCIC], 2005). The local increased prevalence of diabetes may be in part due to the high proportion of South Asian people: it is well known that the incidence of diabetes is increased in the South Asian population (Greenhalgh, 1997). As stated by Williams and Riley (2006), however, the prevalence of diabetes has also been shown to increase with economic deprivation, as choices for and access to exercise, affordable food and health care are diminished.

Conversely Solihull has a population of 212000 (Solihull PCT, 2006) that consists mainly of relatively affluent White people (Solihull PCT, 2004). Solihull has a diabetes prevalence rate of 3.3% (HSCIC, 2005). There is some deprivation in the north of the borough, but, overall, less than 5% of Solihull's population is classed as living in a deprived area (Solihull PCT, 2004). The PCT has 31 GP practices (Solihull PCT, 2006) and a proportion of non-White people of 5.4% (Solihull PCT, 2004).

Similarly, in the author's experience, differences exist between the structure and level of service offered by the community diabetes teams in Eastern Birmingham and Solihull PCTs.

The community diabetes service in Solihull is relatively well established compared with that in Eastern Birmingham. The majority of GPs and practice nurses have participated in the Warwick Diabetes Care course, which has made practice-based diabetes clinics generally available to most people with diabetes. The community diabetes team benefits from a lead nurse and approximately 3.0 whole-time equivalent (WTE) diabetes specialist nurses, and it operates intermediate clinics in the community for people with diabetes needing intensive input and education sessions.

Jackie Webb is a Diabetes Specialist Nurse Manager, Diabetes Centre, Birmingham Heartlands Hospital, Birmingham. The team's referral pathways are organised, documented and tested. In general there appear to be relatively few people with diabetes from Solihull who are not referred for formal preconception care or who do not receive similar care from their GP or practice nurse.

Conversely the diabetes service in Eastern Birmingham is still relatively new. The service does have the benefit of a nurse consultant and a dedicated community consultant. In addition there is 1.0 WTE specialist nurse and 1.0 WTE link worker. Referral pathways have recently been formalised and documented. GPs and practice nurses are participating in the Warwick Diabetes Care course; indeed, some practices offer their own diabetes clinics and insulin initiation. However, the structure of the service is not as well developed as that of its partner Solihull and this undoubtedly is one reason for the limited referral rate to the secondary care-based pre-conception clinic. Nevertheless because of the infancy of the primary care diabetes services many of these people with diabetes attend secondary care for their basic diabetes care, and one would reasonably expect robust referrals from this area.

In truth women with pre-existing diabetes of child-bearing age (13–50 years) 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 and knows how she can do this. Even when this is not the case, the author feels that insufficient emphasis is placed on the essentiality of receiving pre-conception care at the appropriate time.

Other factors affecting access to health care include communication-based and cultural barriers to understanding, as well as difficulty accessing a secondary care service (Williams and Riley, 2006).

## The pre-conception clinic

The pre-conception clinic for referrals for women with diabetes from Eastern Birmingham PCT and Solihull PCT was set up in 2002. It is a nurse-led clinic which currently operates from Birmingham Heartlands Hospital twice a month, and this allows the hospital to have each

month a dedicated clinic for new referrals and a follow-up clinic. Traditionally referrals have been received from primary and secondary care, the latter generally coming from the main diabetes outpatient clinic and the fertility clinic, both of which operate from within the hospital.

Referrals are also received from the maternity service for women with pre-existing diabetes who have had a poor outcome (such as a miscarriage) but may wish to conceive in the future. In addition referrals are received for women who have had previous gestational diabetes and either needed insulin during their pregnancy or had a post-natal glucose tolerance test (GTT) showing impaired fasting or impaired glucose tolerance.

When the clinic started in 2002, GPs were informed of the service by way of an open letter inviting them to refer women with diabetes. Despite this, referral figures from primary care for women with diabetes or previous gestational diabetes remained very low. Further, the ante-natal service at the hospital still had women with preexisting diabetes attending in the early stages of pregnancy who had poorly controlled diabetes or who were taking teratogenic medication. With this in mind, a poster was produced in English, Urdu and Bengali that was aimed at girls and women of child-bearing age with diabetes, inviting them to self-refer to the pre-conception clinic. The poster was sent to all GP practices in 2003 and again in 2004 with the intent that it would be displayed in their waiting areas. It was also sent to other community centres and outpatient locations across the Eastern Birmingham and Solihull boroughs.

Sadly there was little if any improvement in preconception care uptake, and in 2005, in women with pre-existing diabetes, there were several first-trimester miscarriages, two stillbirths and a termination at 24 weeks due to severe congenital malformation, all of which may have been avoided had pre-conception care been sought. It was felt by the hospital diabetes team that either it was failing to get the message of the need for preconception care across to healthcare professionals or the message was not being heeded by the community population. In essence both aspects of this viewpoint proved to be partially right.

From data collected at the hospital it was identified that in 2005 less than 5% of referrals

#### Page points

- 1. The pre-conception clinic for referrals for women with diabetes from Eastern Birmingham Primary Care Trust (PCT) and Solihull PCT was set up in 2002.
- 2. When the clinic started in 2002, GPs were informed of the service by way of an open letter inviting them to refer women with diabetes.
- 3. Despite this, referral figures from primary care remained very low.
- 4. A poster was produced in English, Urdu and Bengali inviting girls and women of child-bearing age with diabetes to self-refer to the preconception clinic; this was sent to all practices in 2003 and again in 2004 with the intent that it would be displayed in their waiting areas.
- 5. However, there was little if any improvement in pre-conception care uptake.

#### Page points

- 1. Midway through 2005, the author's team decided that it was essential to readdress the issue of preconception care uptake.
- 2. Communication problems and cultural differences were identified as the main barriers to understanding the need for pre-conception care.
- 3. Consequently the diabetes team held a meeting with the consultant community midwife, personnel from Sure Start, community-based diabetes nurses and people who organised local 'Action groups' for women.
- 4. As a direct result of this meeting, education relating to basic diabetes and the need for preconception care has been given to key Sure Start personnel for several areas in the author's locality.

were received from primary care. This implied that many girls and women of child-bearing age with pre-existing diabetes were not receiving the care and information they needed pre-conception unless this was being provided by their surgery.

#### Content of clinics

All newly referred women are invited to attend their first appointment with their partner (roughly 60% of women attending the clinic have type 2 diabetes, while the remaining 40% have type 1 diabetes). Their initial appointment is quite lengthy (over an hour) as there is a lot of information 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.

Appendix 1 shows the information that is recorded for attendees and highlights the education given to women with diabetes and their partners at their first visit. 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 (e.g. Richards, 1967); the possibility of a Caesarean section being necessary; the need for 5 mg folic acid daily; the increased risk of hypoglycaemia associated with treatment intensification (Diabetes Control and Complications Trial Research Group, 1996); the need for frequent monitoring of blood glucose; the benefits of tight glycaemic control (such as HbA<sub>1c</sub> <6.5%); and the fact that maintaining tight glycaemic control pre-conception and during pregnancy is very hard work.

Women with diabetes and their partners are invited to see the dietitian, who assesses diet and provides education and advice relating to foods which need to be avoided during the preconception and pregnancy period.

Women with diabetes are informed that they will be reviewed every 2 months in the follow-up clinic with telephone intervention in between. They are provided with written information covering the areas discussed and it is explained that they will be telephoned with the results of their blood tests the following week.

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 it to be requested that the GP changes or adds to medication where necessary). This procedure is replicated when women attend subsequent follow-up appointments.

Following their initial clinic visit, in order to intensify treatment and improve control, 17 women with diabetes have been commenced on a basal–bolus regimen, 12 on twice-daily insulin, one on once-daily insulin and one on pump therapy.

# Challenges

Midway through 2005, following the miscarriages, stillbirths and termination described above, the author's team decided that it was essential to re-address the issue of pre-conception care uptake.

The team was aware that it was failing to reach the most 'at-risk' groups, such as non-English speaking girls and women of child-bearing age requiring insulin therapy because of pre-existing diabetes or previous gestational diabetes. The team also knew that the uptake of post-natal GTTs was poor and felt that the primary care team was at that time unable to provide any more support.

Communication problems and cultural differences were identified as the main barriers to understanding the need for pre-conception care.

Consequently the diabetes team held a meeting with the consultant community midwife, personnel from Sure Start (a government programme providing early education, childcare, and health and family support; www.surestart. gov.uk [accessed 18.04.2006]), communitybased diabetes nurses and people who organised local 'Action groups' for women. The response was very positive; for instance, local groups were sympathetic to the plight and keen to assist in addressing the issues and help with providing whatever support was necessary. As a direct result of this meeting, education relating to basic diabetes and the need for pre-conception care has been given to key Sure Start personnel for several areas in the author's locality. Further, the team has been asked to follow this up with talks given to local parents who use Sure Start facilities.

An awareness event specifically for Somalian women was arranged at a local school in February 2006; this involved using an interpreter, getting basic educational advice translated into Somalian and Arabic, providing blood glucose and blood pressure testing, giving a short talk about diabetes and the need for pre-conception care, and providing lunch. Although attendance was low, the event has led to other localities being identified and other communities targeted. It is also hoped by the author that in the future the team can promote the message of contraception use as a means of birth control, especially in women with poor glycaemic control or who are taking teratogenic medication.

Another challenge is data collection; in order for the author's team to contribute to the overall picture in the West Midlands it is essential that the data collection it conducts is robust and pertinent. One potential problem arises because the author's diabetes centre does not hold its own register of patients. All the nursing interventions are recorded manually onto a paper-based system, which makes searching and comparison relatively arduous. It is essential, the author feels, that this system is replaced with a paperless database to enable fuller analysis of retrospective and current data, which will further enable the targeting of specific areas and populations.

#### Needs

The challenges faced in running the preconception clinic are many and varied and it would not be possible for the author to address all of them within the bounds of this article. Essentially, though, the overall need is to increase awareness among members of the general public, people with diabetes and healthcare professionals.

There is a need to continue to target specific cultural groups so that the most 'at-risk' individuals are reached, and to address cultural issues which are themselves significant barriers to understanding. People with diabetes also want more services locally and there is therefore a need, the author believes, to identify how it would be feasible to offer these within primary care locations. It is hoped that achieving this

will improve the care uptake rate, the did-notattend rate and the level of involvement at clinics, and lead to an emergence of real understanding among the author's local populations, which in itself may lead to changes.

The author believes that this is the way forward. It is not for people with diabetes to identify ways of accessing healthcare professionals; it is for healthcare professionals to identify ways of accessing people with diabetes.

#### The future

The future needs of the service will be determined by the National Institute for Health and Clinical Excellence, who are due to publish recommendations relating to ante-natal care guidelines in 2007.

There is also a need to continue to address the issues relevant to the author's locality and the population served. It is expected that the prevalence of diabetes will increase; therefore, it is reasonable to suggest that the need for preconception care will increase along with the need for other services. This indicates a requirement to be more imaginative and creative regarding the use of healthcare professionals' time, the venues for care and the way in which services are delivered.

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#### Page points

- 1. There is an overall need to increase awareness about pre-conception care among members of the general public, people with diabetes and healthcare professionals.
- 2. There is a need to continue to target specific cultural groups so that the most 'atrisk' individuals are reached, and to address cultural issues which are themselves significant barriers to understanding.
- 3. The author feels that it is not for people with diabetes to identify ways of accessing healthcare professionals, but, rather, it is for healthcare professionals to identify ways of accessing people with diabetes.

	PRE-PREGNANCY CONSULTATION  DATE:					
		LANGUAGE		Inte	RPRETER USED	Y / N
		MARRIED / PARTNER : RELATED				
	CHILDREN: AGES:					-
		OCCUPATION:				
BSTETRIC HISTORY						
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Abortions	Dates of		Reasons			
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Type 1 / Type 2						
Hypertension Y/N						
Hypercholesterolemia						
Other conditions						
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Contraception				-		
Rubella screened						
Eye Clinic frequency		-			-	1 / 1
HBGM Results						
Folic Acid – 4mg / 5mg	/ none Script for	Y / N	Glucago	n Y/N	Script for Y /	N
DUCATION						
Diales due to .						
Risks due to :-			<b>.</b>			
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Appendix 1. The form used for recording information at the first visit to the pre-conception clinic.