

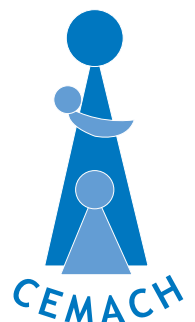
Confidential Enquiry into Maternal and Child Health

Improving the health of mothers, babies and children

PREGNANCY IN WOMEN WITH TYPE 1 AND TYPE 2 DIABETES

2002–2003

England, Wales and Northern Ireland



CEMACH mission statement

Our aim is to improve the health of mothers, babies and children by carrying out confidential enquiries on a nationwide basis and by widely disseminating our findings and recommendations.

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Glossary and abbreviations

abstinence syndrome	Clinical manifestations related to baby withdrawing from maternal substance abuse during pregnancy
anomaly ultrasound scan	Ultrasound scan usually performed at 18–20 weeks of gestation to exclude fetal anatomical abnormality and check the placental site
antepartum haemorrhage	Bleeding from the genital tract from 24 weeks of gestation and before delivery
Apgar score	A system to assess the status of the infant after birth. The Apgar score is based on the following five variables: heart rate, respiratory effort, muscle tone, reflex irritability and colour. Maximum score is 10. It is recorded at 1 minute and 5 minutes after birth.
audit	An examination or review that establishes the extent to which a condition, process, or performance conforms to predetermined standards or criteria
BAPM	British Association of Perinatal Medicine
birth trauma	Mechanical injury that occurs to the baby during the birth process
Black, Asian and Other minority ethnic group	Term encompassing Black, Asian, Chinese and other ethnic groups as distinct from White ethnic origin
blood glucose	Blood sugar plasma value
brachial plexus injury	See Erb's palsy
caesarean section	Surgical abdominal delivery of the baby
Case-control study	A study that compares exposure in subjects who have a particular outcome with those who do not
CEFM	continuous electronic fetal monitoring
congenital anomaly rate	Number of offspring with confirmed congenital anomalies as a proportion of total births (live and still)
congenital malformation/ abnormality/anomaly	A physical malformation (including biochemical) which is present at birth
continuous electronic fetal monitoring	The electronic fetal monitoring of the fetal heart rate and of uterine contractions. The fetal heart rate is recorded by means of either an external ultrasonic abdominal transducer or a fetal scalp electrode. Uterine contractions are recorded by means of an abdominal pressure transducer. The recordings are graphically represented on a continuous paper printout
CTG	Cardiotocograph (see continuous electronic fetal monitoring)
cyanotic episode	In a baby, an episode of bluish discolouration due to excessive concentration of reduced haemoglobin in the blood
DAPHNE	Dose Adjustment for Normal Eating

DCCT	Diabetes Control and Complications Trial
DCCT-aligned HbA_{1c}	HbA _{1c} values that have been measured using a standardised assay and are comparable with data in the Diabetes Control and Complications Trial
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed
detailed retinal assessment	Examination of the fundi through pupils which have been dilated with eye drops
diabetic retinopathy	A complication of diabetes affecting the blood vessels in the retina at the back of the eye, which can affect vision. There may be bleeding from retinal vessels (non-proliferative retinopathy) or the development of new abnormal vessels (proliferative retinopathy)
early neonatal death	Death of a live born baby occurring less than 7 completed days from the time of birth
EDD	estimated delivery date
elective caesarean section	A caesarean section which is timed to suit the woman and health professionals
emergency caesarean section	A caesarean section where delivery is expedited due to concerns about maternal and/or fetal wellbeing
Erb's palsy	Injury to the nerve roots of the brachial plexus of an arm mainly related to birth trauma and leading to various degree of weakness of the affected arm which may resolve during the first year of life
EUROCAT	European Surveillance of Congenital Anomalies
FBS	fetal blood sampling
fetal blood sampling	A test performed in labour with the purpose of obtaining a capillary blood sample from the baby to check for fetal wellbeing
fetal death	Death before complete expulsion or extraction from its mother of a recognisable fetus, irrespective of duration of pregnancy. After separation, the fetus does not show any evidence of life (based on World Health Organization recommended definition)
fetal surveillance	The process of performing fetal wellbeing tests (these may include ultrasound scans, fetal and placental Dopplers, biophysical profiles and fetal heart monitoring)
fructosamine	A test which measures the amount of glucose-bound serum protein and which reflects how well the diabetes has been controlled over the previous 2–3 weeks. It is used in circumstances where the HbA _{1c} test (see HbA_{1c}) is not reliable due to anaemia or to a haemoglobin variant
gestation	The time from conception to birth. The duration of gestation is measured from the first day of the last normal menstrual period
glucagon kit	Glucagon has the opposite effect of insulin; that is, it increases the amount of glucose in the blood. The kit contains freeze-dried glucagon as a powder for injection with 1 mg glucagon and a 1-ml syringe of glycerin. The glycerin is mixed with the glucagon powder prior to injection

glucose electrode	Blood glucose measurement using electrochemical biosensors
glycaemic control test	A test that assesses how well the diabetes has been controlled over a period of time
haematopoiesis	The formation and development of blood cells involving both proliferation and differentiation from stem cells. In adult mammals, this usually occurs in bone marrow
HbA_{1c}	Glycated haemoglobin
HbA_{1c} test	A test which measures the amount of glucose-bound haemoglobin and reflects how well the diabetes has been controlled over the previous 2–3 months
high-dependency care	<p>Criteria for receipt of high-dependency care are:</p> <ul style="list-style-type: none"> • receiving NCPAP for any part of the day but not fulfilling any of the criteria for intensive care • below 1000 g current weight and not fulfilling any of the criteria for intensive care • receiving parenteral nutrition • having convulsions • receiving oxygen therapy and below 1500 g current weight • requiring treatment for neonatal abstinence syndrome • requiring specified procedures that do not fulfil any criteria for intensive care: <ul style="list-style-type: none"> – care of an intra-arterial catheter or chest drain – partial exchange transfusion – tracheostomy care until supervised by a parent – requiring frequent stimulation for severe apnoea
hyperinsulinism	<p>(British Association of Perinatal Medicine, 2001)</p> <p>Condition related to an increase in insulin hormone secretion (as seen in infants of mothers with diabetes during pregnancy) which: a) leads to hypoglycaemia in the baby; and b) prevents the formation of ketone bodies as alternative fuel for the body (see ketogenesis)</p>
hypertensive disorder of pregnancy	High blood pressure with or without proteinuria, which develops for the first time after 20 weeks of pregnancy
hypoglycaemia	Low blood plasma sugar level
hypoketonaemic hypoglycaemia	Low blood plasma sugar level with no formation of ketone bodies
iatrogenic	Due to medical intervention
ICD10	International Classification of Diseases, Revision 10
IMD	Index of Multiple Deprivation
<i>in utero</i> loss	Death prior to complete expulsion or extraction from its mother of a recognisable fetus, irrespective of duration of pregnancy. After separation, the fetus does not show any evidence of life
induction of labour	The process of attempting to start labour (see spontaneous labour). A combination of pharmacological and physical methods may be used
instrumental vaginal delivery	Assisted vaginal delivery of the baby using ventouse or forceps

insulin	A peptide hormone secreted by the islets of Langerhans in the pancreas that enables the body to metabolise and use glucose. Lack of or insensitivity to insulin results in diabetes
intensive care	Criteria for receipt of intensive care are: <ul style="list-style-type: none"> • receiving any respiratory support via a tracheal tube and in the first 24 hours after its withdrawal • receiving NCPAP for any part of the day and less than 5 days old • below 1000 g current weight and receiving NCPAP for any part of the day and for 24 hours after withdrawal • less than 29 weeks of gestational age and less than 48 hours old • requiring major emergency surgery, for the preoperative period and postoperatively for 24 hours • requiring complex clinical procedures: <ul style="list-style-type: none"> ○ full exchange transfusion ○ peritoneal dialysis ○ infusion of an inotrope, pulmonary vasodilator or prostaglandin and for 24 hours afterwards • any other very unstable baby considered by the nurse-in charge to need one-to-one nursing • a baby on the day of death
interquartile range	The spread of a set of values between which 25% (25th centile) and 75% (75th centile) of these values lie
intrauterine death/ intrauterine fetal death	Intrauterine (fetal) death is death of the fetus within the uterus before delivery
ketogenesis	The formation of ketone bodies (substances produced by the body during starvation bringing energy by breaking down fats)
legal abortion	In England and Wales, term used to describe the deliberate ending of a pregnancy, under the provisions of the current law (1967/1992 Act of Parliament), with the intention that the fetus will not survive
macrosomia	Oversized baby as seen for example as a consequence of the effect of diabetes during pregnancy. Generally defined as having a birth weight above the 90th centile for gestation
maternal death	Death of a woman while pregnant or within 42 days of the end of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes
maternal death, coincidental	Deaths from unrelated causes which happen to occur in pregnancy or the puerperium
maternal death, direct	Death of a woman resulting from obstetric complications of the pregnancy state (pregnancy, labour and puerperium), from interventions, omissions, incorrect treatment or from a chain of events resulting from any of the above

maternal death, indirect	Death of a woman resulting from previous existing disease, or disease that developed during pregnancy and which was not due to direct obstetric causes, but which was aggravated by the physiologic effects of pregnancy
maternal death, late	Death occurring between 42 days and 1 year after abortion, miscarriage or delivery due to direct or indirect maternal causes. CEMACH also considers cases from unrelated causes that occur within 1 year of pregnancy, i.e. late coincidental
maturity onset diabetes of the young (MODY)	A group of autosomal dominant disorders in young people each caused by a single gene defect, associated with decreased insulin production and varying degrees of clinical severity
miscarriage	Spontaneous ending of a pregnancy before viability (currently taken as 24 weeks of gestation)
multidisciplinary clinic	A clinic with access to care from health professionals in more than one discipline. For diabetes, the disciplines recommended are obstetrics, diabetology, nursing, midwifery and dietetics
multiple pregnancy	Pregnancy where there is more than one fetus within the uterine cavity
NCPAP	neonatal continuous positive airway pressure
neonatal care	Standard categories for hospitals providing neonatal intensive and high dependency care have been defined by the British Association of Perinatal Medicine (BAPM, 2001). See intensive care, high-dependency care, special care, normal care
neonatal death	Death of a live born baby before the age of 28 completed days
neonatal death rate	The number of neonatal deaths (i.e. occurring within the first 28 days of life) per 1000 live births
neonatal respiratory distress syndrome	Caused by surfactant deficiency, usually in premature babies and causes respiratory distress, usually occurring within 4 hours of birth
neural tube defect	A major birth defect caused by abnormal development of the neural tube, the structure present during embryonic life which later gives rise to the central nervous system (brain and spinal cord)
normal care (postnatal ward)	Care provided for babies who themselves have no medical indication to be in an intensive care unit in hospital (BAPM, 2001) and can therefore stay with their mother on the postnatal ward
NSF	National Service Framework
NTD	Neural tube defect
obstetric cholestasis	A liver disorder of pregnancy characterised by a reduction in the flow of bile from the liver. Associated with increased fetal mortality
offspring	Term encompassing live births, <i>in utero</i> losses after 20 completed weeks of gestation and terminations of pregnancy for congenital anomaly
OHA	oral hypoglycaemic agents

oral hypoglycaemics/oral hypoglycaemic agents	Medicines taken as pills, which are used to help lower blood sugar levels in people with diabetes. There are different types of oral hypoglycaemics; they can be used on their own, in combination with other OHAs or in combination with insulin
parity	The number of viable infants that a woman has delivered. Viability is currently accepted from 24 weeks of gestation onwards
perinatal mortality rate	The number of stillbirths and early neonatal deaths per 1000 live and stillbirths
placenta praevia	Placenta situated wholly or partially within the lower uterine segment
placental insufficiency	Impairment of placental blood flow leading to impaired fetal growth and nutrition
polyhydramnios	Excess amniotic fluid
PPROM	preterm prelabour rupture of the membranes
preconception care service	A preconception care service for women with diabetes is a multidisciplinary service which aims to provide information about diabetes and pregnancy, assess for and treat diabetes complications, review drug medication and work together with the woman to achieve optimal glycaemic control before conception
premature rupture of membranes	Spontaneous rupture of the membranes before labour
preterm delivery	Delivery before 37 ⁺⁰ weeks of gestation
preterm labour	Labour before 37 ⁺⁰ weeks of gestation
prevalence	The proportion of individuals in a population having a disease
primigravida	A woman who is in her first pregnancy
rhesus isoimmunisation	Haemolytic anaemia of the fetus or newborn caused by a rhesus negative mother's anti-rhesus (anti-D) antibodies affecting the red blood cells of her rhesus positive baby
shoulder dystocia	Any documented evidence of difficulty with delivering the shoulders after delivery of the baby's head
SIGN	Scottish Intercollegiate Guidelines Network
special care	Care provided for all babies not receiving intensive or high dependency care but whose carers could not reasonably be expected to look after them in hospital or at home (BAPM, 2001)
spontaneous labour	Regular painful contractions leading to progressive cervical effacement and dilatation
spontaneous preterm delivery rate	The percentage of babies delivered between 24 ⁺⁰ and 36 ⁺⁶ weeks of gestation, inclusive, due to preterm labour, with the denominator being all babies delivered from 24 ⁺⁰ weeks of gestation onwards
spontaneous vaginal delivery	A baby delivering vaginally without instrumental assistance; usually refers to babies born with the head presenting first
stillbirth rate	The number of stillbirths per 1000 total births (live births and stillbirths)

stillbirth, legal definition	A child that has issued forth from its mother after the 24th week of pregnancy and which did not at any time after being completely expelled from its mother breathe or show any other signs of life (Section 41 of the Births and Deaths Registration Act 1953 as amended by the Stillbirth Definition Act 1992)
Super Output Area	Geography for the collection and publication of small area statistics
termination of pregnancy	See legal abortion
transitional care	Care of term or near-term babies not needing high-dependency or intensive care which can safely be delivered without being separated from their mothers in a so-called transitional care unit or nursery
transitional care unit	In this facility, parents can look after their own infants with some supervision from trained neonatal unit staff. Transitional care is interpreted in a wide range of ways. There is undoubtedly a group of babies who are not well enough to be looked after on regular postnatal wards and yet there are strong advantages in their parents carrying out the bulk of their care. Such infants include babies with hypoglycaemia when it is believed there is no underlying serious pathology, babies of 34 and 35 weeks of gestation who are establishing breastfeeding and babies who have mild respiratory disease but do not require oxygen supplementation. Phototherapy may safely be given in transitional care. The transitional care area can also be used by mothers who are gaining confidence immediately prior to discharge home
trimester	One of the 3-month periods into which pregnancy is divided. The first trimester is 0–13 weeks of gestation, the second trimester is 14–26 weeks of gestation and the third trimester is 27 weeks of gestation until birth.
unstable lie	Unpredictable and frequent changes in the way the fetus lies relative to the long axis of the uterus after 37 weeks of gestation
vaginal breech	A baby delivering vaginally with the breech presenting first

Foreword

With diabetes affecting a large and growing number of women of childbearing age, this report and its comprehensive analysis of care before, during and after pregnancy is very timely. The Confidential Enquiry into Maternal and Child Health (CEMACH) has carried out what is believed to be the world's largest ever survey of pregnant women with diabetes and their findings make compelling and, in some instances, disturbing reading for both healthcare professionals working with diabetes and their female patients.

The detailed evidence on the outcomes of pregnancy for both mother and child and the increased risk of stillbirths, premature or caesarean delivery and malformation provide valuable insights to healthcare professionals as well women with diabetes considering pregnancy.

Their findings and recommendations pose a considerable number of challenges to local NHS organisations, diabetes professionals and women with diabetes who are or who wish to become pregnant.

For local NHS organisations, the focus will be on the increased resources and changes in care processes that will be required to provide the highest possible standard of care for their female patients. They will need to ensure that a woman with diabetes receives an effective service that integrates prepregnancy counselling, primary care responsibilities and essential specialist care. In particular, it is critical that women of childbearing age are supported to have much improved blood glucose levels when they enter pregnancy. This may mean looking at existing structures, workforce skills and systems to ensure they are working effectively together and developing entirely new approaches to involving women based in the very diverse communities in which they live. Outcomes must be improved and inequalities reduced.

For the diabetes healthcare community, it means working within integrated services and strengthening multidisciplinary teams in both primary and specialist care, to ensure that pregnant women with diabetes have a seamless pathway from wishing to become pregnant to delivering a healthy child. Ensuring along the way that their patients receive all the essential support and information to truly involve them in managing their own condition.

For women with diabetes who are planning to become pregnant, there is a real opportunity to increase their chances of having a healthy pregnancy. By actively working with their local care teams as well as specialist services and by becoming involved in the patient education and advice that will be offered they can make a real difference to their pregnancy and their child.

Although the main message of this report is that there is an increased risk of experiencing a stillbirth, induced and caesarean delivery and of having a baby with a congenital anomaly, there is good news. CEMACH found that 59% of pregnancies went to term and, after 28 days, 86% of babies were alive and without any diagnosed major congenital anomaly. So, although women with diabetes need to be aware of the risks, they must also be aware that these can be reduced if not eliminated; that there is a good chance for a healthy pregnancy and a healthy baby.

Sue Roberts
National Clinical Director for Diabetes

1 Background

1.1 Introduction

Diabetes is a common medical disorder complicating pregnancy, affecting approximately one pregnant woman in 250 in the United Kingdom (UK). There are two major types of diabetes. Type 1 diabetes occurs because the insulin-producing cells of the pancreas have been destroyed by the body's immune system and typically develops in children and young adults. Type 2 diabetes is more commonly diagnosed in adults over the age of 40 years, although, increasingly, it is appearing in young people.¹ In this condition, insulin is produced but is insufficient for the body's needs. There is also a degree of insulin resistance, where the cells in the body are not able to respond to the insulin that is produced. In England, about 85% of the diabetic population has type 2 diabetes but type 1 diabetes is more frequent in pregnancy.²

Diabetes is becoming more common. Type 1 diabetes is increasing in children, mainly in those under the age of five.² Type 2 diabetes is increasing in all age groups, including children and young people, but predominantly among the Black, Asian and Other ethnic minority groups.² This lifelong disease impacts on lifestyle, health and wellbeing.

Women with diabetes are at an increased risk of losing a baby during pregnancy, having a baby with a congenital anomaly or the baby dying during the first year of life. These risks were measured in the mid 1990s by a number of regional studies in the UK. They found a three- to five-fold increase in the perinatal mortality rate and a four- to ten-fold increase in the congenital malformation rate compared with that of the general population.³⁻⁶ This was disappointing in light of the St. Vincent Declaration in 1989, which set a 5-year target to achieve similar pregnancy outcomes in women with diabetes to those without the condition.^{6,7} A confidential enquiry review of a sample of pregnancies in England, Wales and Northern Ireland, conducted in 1997, also identified a substantial proportion of mothers with diabetes whose babies had died who received suboptimal care.⁸

Responding to this, the Confidential Enquiry into Maternal and Child Health (CEMACH) initiated a national enquiry programme aimed at improving the quality of maternity care and pregnancy outcomes for women with pre-gestational diabetes in England, Wales and Northern Ireland. This programme of work comprises three linked studies:

1. A **survey of maternity services** for women with type 1 and type 2 diabetes in 2002.⁹
2. A **descriptive study** on all pregnancies of women with pre-gestational diabetes who delivered or booked between 1 March 2002 and 28 February 2003, with follow up to pregnancy outcome at 28 days after delivery. This study included an audit of standards of care for women with pre-gestational diabetes.
3. A **confidential enquiry**, consisting of multidisciplinary panel case reviews. This comprises a case-control study into the impact of clinical care on pregnancy outcome and an audit of care during and after pregnancy, for women with pre-gestational diabetes.

The survey of maternity services compared service provision for women with diabetes in England, Wales and Northern Ireland in 2002 with those available 10 years previously.⁹

While improvements in the provision of specialist staff were found, there were three main areas of concern: nearly one-third of units did not provide multidisciplinary clinics; an equivalent proportion of units routinely admitted the baby of a mother with diabetes to the neonatal unit without a specific medical indication; and there appeared to be poor provision of prepregnancy care, with little development in this area over 10 years.

This report describes the findings from the second study; that is, **the descriptive study**, in CEMACH's diabetes programme of work. This study had two principal aims:

1. To provide national outcome rates for babies of women with pre-existing diabetes, as outlined below:
 - a. perinatal mortality rates
 - b. stillbirth rates
 - c. neonatal mortality rates
 - d. congenital anomaly rates.
2. To assess the degree to which clinical standards of care were met for women with pre-gestational diabetes and their babies from preconception to the postnatal period.

1.2 Methods

1.2.1 Data collection

Pre-gestational diabetes was defined as either type 1 or type 2 diabetes that had been diagnosed at least 1 year before the woman's estimated delivery date (EDD). Data were collected on women at any stage (from booking to delivery) between 1 March 2002 and 28 February 2003 and followed through to outcome of baby at 28 days.

All maternity units in England, Wales and North Ireland expecting to provide some aspect of diabetes maternity care in 2002–03 were provided with information leaflets, notification forms and questionnaires. There were 231 maternity units recorded as providing some form of maternity care to women with diabetes in this period.

Information leaflets were given to all women with pre-gestational diabetes prior to the data collection. The notification forms were sent to CEMACH regional offices upon the identification of a pregnant woman as having pre-gestational diabetes. An additional questionnaire was subsequently filled in either concurrent to the pregnancy or retrospectively based on medical records. The questionnaire was completed by health professionals at the unit attended by the pregnant women. The questionnaire included demographic characteristics, type of diabetes, labour, delivery and outcome details up to day 28 for the baby, and a number of additional questions relating to care from prepregnancy to the neonatal period (see Appendix A). The data collection was co-ordinated, validated and entered on to a centralised database at a regional level.

During the study, 3761 women were notified to CEMACH and accounted for 3836 pregnancies. Within this group, there were 28 women for whom the type of diabetes was either maturity onset diabetes of the young (11) or other/unknown (17). These 28 pregnancies have been excluded in all descriptions and analyses throughout this report. This report is therefore based on 3808 pregnancies in 3733 women who had type 1 or type 2 diabetes prior to pregnancy and booked or delivered between 1 March 2002 and 28 February 2003 (Table 1.1).

Table 1.1: Figures used throughout report

	Total study population (n)	Deliveries between 1 March 2002 and 28 February 2003 ^a (n)
Women in study	3733	–
Pregnancies	3808	–
Total babies	3876	–
Pregnancies ongoing after 24 weeks of gestation	3474	–
Live births delivering after 24 completed weeks of gestation	3449	2291
Live births delivering before 24 complete weeks of gestation	2	2
Total live births	3451	2293
Stillbirths	87	63
Total births	3538	2356

^a These figures are used for prevalence and perinatal mortality figures to allow comparisons with other national data collections.

Not included in the programme were women who actively requested for their data not to be included, those who did not seek medical attention during pregnancy and those women who were not reported to the enquiry by the health professionals caring for them during pregnancy.

As this study was part of a national clinical audit, ethical approval and consent were not specifically sought at the outset of the project. In 2001, Section 60 of the Health and Social Care Act was introduced to allow organisations to obtain patient-identifiable information for medical purposes in circumstances where it was impracticable to obtain informed consent from the patients concerned. CEMACH received Section 60 approval for its programme of work in December 2003.

1.2.2 Congenital anomalies and perinatal mortality

Congenital anomalies

Data were collected on presumed congenital anomalies in the antenatal period and up to 28 days of life for all live births, all fetal losses after 20 completed weeks of gestation and all terminations of pregnancy at any gestation. Any reported diagnosis was subsequently confirmed by postmortem findings, genetic results or correspondence between health professionals. Data are presented in this report for confirmed anomalies only. These anomalies were coded according to the 10th revision of the International Classification of Diseases (ICD10). Individual codes were grouped according to the classification system used by the European Surveillance of Congenital Anomalies (EUROCAT) and can be seen in Appendix B.¹⁰ Minor congenital anomalies were excluded, a list of which is provided in Appendix C. Where information was limited, coding was validated by an independent paediatrician.

Perinatal mortality

Stillbirth was defined as an *in utero* loss delivering after 24 completed weeks of gestation, neonatal death as the death of a live birth (born at any gestation) up to 28 days after birth and perinatal death as a stillbirth or death of a live birth (born at any gestation) up to 7 days after birth.

Perinatal mortality rates are based on the births between 1 March 2002 and 28 February 2003, as opposed to the entire study sample. This therefore excludes births to women booking at or before 28 February 2003 but delivering after this date (Table 1.1). This approach, using

deliveries in 1 calendar year, allows direct comparisons with other reported national perinatal mortality rates.

1.2.3 Audit of standards of care

The standards of care for Chapters 6 and 9 in this report (Appendix D) were drawn up at the outset of the study by a multidisciplinary professional group of senior clinicians with expertise in diabetic pregnancy (the Diabetes Multidisciplinary Resource Group). The standards were derived from the most contemporary UK-based national guideline for the management of diabetes in pregnancy available, the Scottish Intercollegiate Guidelines Network (SIGN) guideline No. 9.¹¹ This was subsequently updated in November 2001.¹² The National Service Framework (NSF) for Diabetes standards were published in December 2001, which is the current guideline used for the National Health Service (NHS) in England.² There is good agreement between all the guidelines.

The assessment of clinical care in this audit was based on information contained in the questionnaire filled in by the health professionals (see 1.2.1). This questionnaire contained a number of free-text fields which collected information on 'reasons for' or 'indications for' certain events occurring during pregnancy and the neonatal period. This free-text information was subsequently categorised by an individual clinician (obstetrician and paediatrician, as appropriate) for the purposes of exploring the data further.

1.3 Limitations

Some important maternal and neonatal outcomes were not covered in the data collection, in particular renal function and hypoglycaemic episodes of the mother and hypoglycaemic episodes in the newborn. In addition, certain confounding factors for adverse maternal and neonatal outcome were not collected including body mass index, socioeconomic status and smoking. There are thus some limitations with conclusions that can be drawn regarding the associations between certain risk factors and outcomes.

Tables where free-text information has been categorised, as detailed above in section 1.2.3, are footnoted throughout the report. Categorisation was based purely on text contained in the questionnaire, with no additional information collected directly from case notes. Results contained within these tables should therefore be interpreted with a degree of caution.

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2 Prevalence of diabetes in pregnancy

KEY FINDINGS

- Diabetes in pregnancy varies across England, Wales and Northern Ireland from 1 in 240 to 1 in 333 births.
- The areas of highest prevalence of diabetes in pregnancy do not necessarily coincide with the areas of highest prevalence of diabetes in the general population.

2.1 Introduction

Diabetes is a major public health problem in England, Wales and Northern Ireland with approximately 1.6 million people living with the diagnosis of type 1 or type 2 diabetes in 2004.¹ Diabetes has long been recognised as a maternal factor which can lead to complications during pregnancy. Understanding the needs of women with diabetes and quantifying the number of pregnancies affected by diabetes is important for the planning and allocation of resources for services.

The overall or crude prevalence of diabetes (type 1 and type 2 combined) is dependent upon the age structure of the population as risk of diabetes increases substantially with age. Prevalence estimates of 0.3% in people aged below 30 years and 3.4% in people aged between 30 and 60 years old have been given by the PBS Diabetes Population Prevalence Model.² The prevalence in women aged between 15 and 44 years of diagnosed type 1 and type 2 diabetes of the population of England, Wales and Northern Ireland is estimated at 0.68% and 0.36%, respectively.¹

This chapter describes the national and regional prevalence figures for type 1 and type 2 diabetes in pregnancy. The regions described are coterminous with the nine government offices for the regions in England plus Wales and Northern Ireland, according to boundaries as of 1 March 2003.

2.2 National and regional prevalence 2002–03

We estimated the prevalence of diabetes in pregnancy by measuring the prevalence of babies born (live or stillborn) to women with diabetes.

Prevalence figures were calculated using all births in one calendar year (between 1 March 2002 and 28 February 2003) to allow comparisons with regional birth figures. There were 2356 births (stillbirths and live births) to women with pre-gestational diabetes delivered between 1 March 2002 and 28 February 2003. Table 2.1 gives the prevalence of diabetes in pregnancy nationally and regionally according to type of diabetes. Women were assigned to a region based on the maternal postcode of residence. Where the postcode was missing or

Table 2.1: Regional distribution of births by maternal region of residence and type of diabetes

Maternal region of residence ^a	Total births 2002 (n) ^b	Births to women with type 1 & type 2 diabetes		Births to women with type 1 diabetes		Births to women with type 2 diabetes	
		(n)	Proportion of all births (%)	(n)	Proportion of all births (%)	(n)	Proportion of all births (%)
England	568954	2176	0.38	155	0.27	624	0.11
North East	26433	108	0.41	80	0.30	28	0.11
Yorkshire and Humberside	55871	168	0.30	118	0.21	50	0.09
North West	75076	288	0.38	201	0.27	86	0.11
West Midlands	61424	256	0.42	167	0.27	89	0.14
East Midlands	45294	189	0.42	154	0.34	35	0.08
East of England	60482	229	0.38	182	0.30	47	0.08
London	106302	418	0.39	232	0.22	186	0.17
South East	88512	331	0.37	262	0.30	69	0.08
South West	49560	194	0.39	160	0.32	34	0.07
Wales	30372	105	0.35	91	0.30	14	0.05
Northern Ireland	21504	71	0.33	59	0.27	12	0.06
Engl., Wales & NI	620830	2356	0.38	1706	0.27	650	0.10

^a Figures for the North West include cases from the Isle of Man; figures for the South East include cases from the Channel Islands.
^b Source for total births: ONS and NI GRO.

inaccurate ($n = 42$), women were assigned to the region of birth according to the hospital of delivery.

Births to women with pre-gestational diabetes accounted for 0.38% of all births in England, Wales and Northern Ireland, or one in every 264 births. The lowest prevalence of pre-gestational diabetes in pregnancy was seen in Yorkshire and Humberside, one in every 333 births, with the highest prevalence in the West Midlands, one in every 240 births.

Type 1 diabetes accounted for 0.27% of all births, or one in every 364 births. The lowest prevalence of type 1 diabetes in pregnancy was seen in Yorkshire and Humberside, one in every 473 births, with the highest in the East Midlands, one in every 294 births.

The prevalence of type 2 diabetes accounted for 0.10% of all births, or one in every 955 births. The lowest prevalences of type 2 diabetes in pregnancy were seen in Wales and Northern Ireland, one in every 2169 and 1792 births, respectively, with the highest prevalences seen in the West Midlands and London, one in every 690 and 572 births, respectively.

When comparing the geographical distribution of diabetes in the general population, it appears that the areas with the highest prevalence of diabetes overall do not necessarily coincide with the areas of highest prevalence of diabetes in pregnancy.²

Type 2 diabetes accounted for 27.6% of diabetes in pregnancy in England, Wales and Northern Ireland and varied from 13.3% in Wales to 44.5% in London (Figure 2.1).

2.3 Discussion

Births to women with pre-gestational diabetes account for 0.38% (1 in 264) of all births within the population of England, Wales and Northern Ireland, ranging from 0.30% to 0.42%.

There is considerable variation in the regional distribution of diabetes with births to women with type 2 diabetes accounting for between 13.3% and 44.5% of all births to women with diabetes (type 1 and 2). This regional variation can be partly explained by the socio-demographic

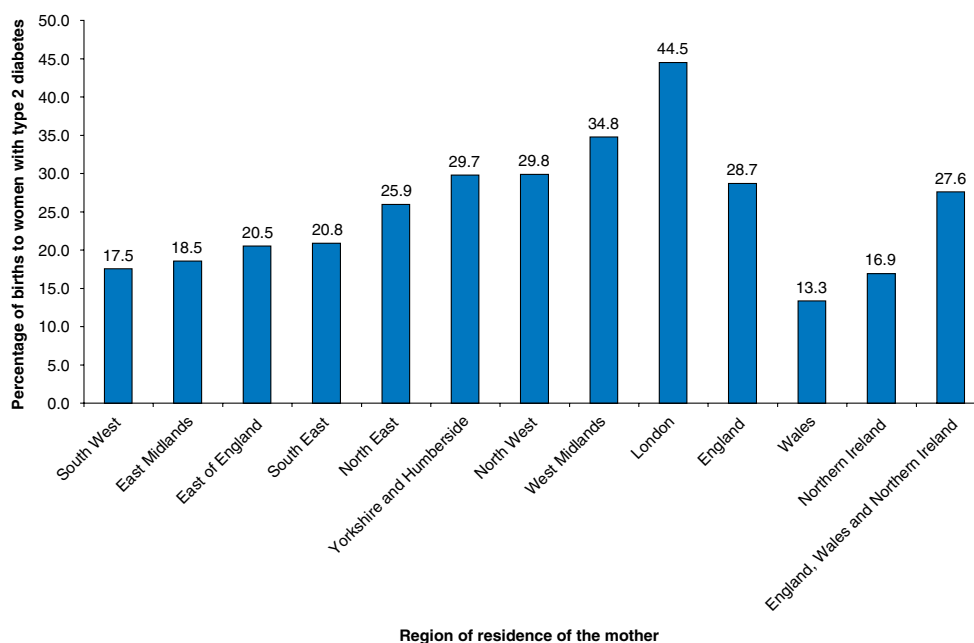


Figure 2.1: Proportion of births to women with type 1 and type 2 diabetes by maternal region of residence; figures for the North West include cases from the Isle of Man; figures for the South East include cases from the Channel Islands (source for national data: ONS)

characteristics of these regions with areas of high ethnic diversity and/or social deprivation having a greater number of women with type 2 diabetes.

It is possible, however, that some of the variation seen is due to differences in ascertainment on a regional basis. It was not possible to find an alternative source of data against which to validate the numbers of births to women with pre-existing diabetes within the population of England, Wales and Northern Ireland at the time of the study. As such, the potential levels of under-ascertainment on a regional basis cannot be quantified at this stage.

As the incidence of diabetes continues to increase, particularly that of type 2 diabetes in children and young adults,^{3,4} there are significant implications for maternity care in the next decade as these women enter childbearing age. This is particularly important, as evidence suggests that the offspring of women with diabetes are themselves at an increased risk of developing diabetes.⁵

2.4 Conclusion

There is considerable variation in the prevalence of diabetes in pregnancy across England, Wales and Northern Ireland. The relative distribution of type of diabetes also shows substantial variation, with type 2 diabetes a much larger contributing factor in some regions, such as London and the West Midlands. This, combined with the apparent finding that areas of high prevalence of diabetes in pregnancy do not necessarily coincide with areas of high prevalence of diabetes in the entire population, needs to be considered in the planning of diabetes services. Pregnancy services may need to be targeted in different areas to other diabetes services.

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3 Description of the women

KEY FINDINGS

- Women with type 1 diabetes are different from women with type 2 diabetes with respect to certain demographic characteristics such as age, ethnicity and parity.
- There is a significant gradient of deprivation seen in women with diabetes, most pronounced for women with type 2 diabetes of Black or Other ethnic minority ethnic origin.

3.1 Introduction

This chapter describes the 3733 women who had type 1 or type 2 diabetes prior to pregnancy and booked or delivered between 1 March 2002 and 28 February 2003. Seventy-three women had more than one pregnancy within this time period (70 with two pregnancies and two with three pregnancies). For the purposes of the following descriptions and for consistency with the remainder of the report, these women are counted once for each pregnancy episode. Women with more than one pregnancy were no different to women with only one pregnancy with respect to type of diabetes, age at delivery, ethnicity or deprivation.

3.2 Maternal characteristics

Table 3.1 shows certain demographic characteristics of the women included within the study.

Table 3.1: General characteristics of study population

	Type 1 (N = 2767)	Type 2 (N = 1041)	All (N = 3808)
Median age at delivery (years) <i>n</i> [IQR]	30.0 [26, 34]	33.5 [30, 37]	31.0 [27, 35]
Ethnicity <i>n</i> (%):			
White	2526 (91.3)	533 (51.2)	3059 (80.3)
Black African	37 (1.3)	84 (8.1)	121 (3.2)
Black Caribbean	35 (1.3)	49 (4.7)	84 (2.2)
Black other	7 (0.3)	7 (0.7)	14 (0.4)
Indian	38 (1.4)	72 (6.9)	110 (2.9)
Pakistani	40 (1.4)	163 (15.7)	203 (5.3)
Bangladeshi	15 (0.5)	71 (6.8)	86 (2.3)
Chinese	2 (0.1)	5 (0.5)	7 (0.2)
Other	62 (2.2)	54 (5.2)	116 (3.0)
Not known	5 (0.2)	3 (0.3)	8 (0.2)
Primigravid <i>n</i> (%)	1263 (45.7)	244 (23.5)	1507 (39.7)
Median age at onset of diabetes (years) <i>n</i> [IQR]	15 [10, 23]	29 [25, 33]	20 [11, 28]
Median duration of diabetes (years) <i>n</i> [IQR]	13 [7, 20]	3 [2,6]	9 [4, 17]

IQR = interquartile range.

3.2.1 Type of diabetes

Women with type 2 diabetes accounted for 27.3% of women in this study. Of the 1041 women with type 2 diabetes, 276 (26.5%) were documented as having been on insulin before their last menstrual period.

3.2.2 Age

The median age of the women with type 1 and type 2 diabetes at delivery was 31 years which was not significantly different from the general population.¹ Women with type 2 diabetes were on average older at onset of diabetes (median age 29 years compared with 15 years for women with type 1 diabetes) and thus had a shorter duration of the disease. This reflects the difference in disease profile between the two types of diabetes. This is also reflected in the higher age at delivery of the women with type 2 diabetes compared with those women with type 1 diabetes. Within this pregnancy cohort, there were 67 women with type 2 diabetes with an age of onset of diabetes of less than 20 years.

3.2.3 Ethnicity

When women with type 1 and type 2 diabetes were considered together, maternal ethnic origin was not significantly different to the general maternity population of England which reports 80.3% White, 5.8% Black (Black Caribbean, Black African and Black Other), 10.5% Asian (Indian, Pakistani and Bangladeshi) and 3.4% Chinese and other ethnic background.² A much higher proportion of women with type 2 diabetes were of Black, Asian or Other ethnic minority origin compared with women with type 1 diabetes (48.5% versus 8.5%), again largely reflecting the profile of the disease.

3.2.4 Gravidity

A total of 1507 women (39.7%) were primigravid. Women with type 1 diabetes were significantly more likely to be primigravid (Table 3.1) ($P < 0.001$). This difference is largely explained by the higher median age at delivery of women with type 2 diabetes. This itself will be partly driven by the later age of onset of type 2 diabetes.

3.2.5 Deprivation

The relationship of diabetes in pregnancy with deprivation was explored by the application of an Index of Multiple Deprivation (IMD) score.³ This was based on the postcode of residence of the women and the corresponding Super Output Area as defined by the Office for National Statistics. Each Super Output Area has a deprivation score calculated using multiple-source data. These deprivation scores were ranked and quintiles of deprivation derived for the national population. It should be noted that these quintiles are based on the entire population of England, not just the maternity population. Women within this study were then placed into the appropriate quintile of deprivation. As this measure is based only on the population of England, women within our study who were normally resident in Wales and Northern Ireland were excluded for the purposes of Tables 3.2, 3.3, 3.4.

Due care should be taken when interpreting these data as there are limitations when applying population based statistics at the individual level. No individual-level data on occupation or social class were collected in the data-capture questionnaire for this study.

There was a higher proportion of women with type 2 diabetes than expected in the higher quintile categories, particularly in the most deprived quintile (45.1% compared with expected 20%). There was only a slight increase in the proportion of women in the fifth quintile for women with type 1 diabetes (Table 3.2).

The relationship between type of diabetes and deprivation was further explored according to ethnic origin (Tables 3.3 and 3.4). For women of White ethnic origin, there was a clear increase in the numbers of type 2 women with increasing quintile of deprivation. Over 30% of White women with type 2 diabetes fell into the most deprived quintile, compared with the expected 20%. No such increase was seen in women of White ethnic origin with type 1 diabetes.

For women of Black or Other ethnic minority origin, this increase was seen in women with both type 1 and type 2 diabetes. Over one-third of all women of Black, Asian or Other ethnic minority origin with type 1 diabetes fall in to the most deprived quintile. The gradient was

Table 3.2: Quintiles of deprivation score according to type of diabetes, England only

Quintile of Index of Multiple Deprivation score	Type of diabetes <i>n</i> (%)		Total <i>n</i> (%)
	Type 1	Type 2	
1 (least deprived)	428 (17.0)	68 (6.8)	496 (14.1)
2	472 (18.8)	109 (10.9)	581 (16.5)
3	499 (19.8)	139 (13.9)	638 (18.2)
4	503 (20.0)	225 (22.5)	728 (20.7)
5 (most deprived)	551 (21.9)	451 (45.1)	1002 (28.5)
Missing postcode	61 (2.4)	9 (0.9)	70 (2.0)
Total	2514 (100.0)	1001 (100.0)	3515 (100.0)

Table 3.3: Women of White ethnic origin; quintiles of deprivation score according to type of diabetes, England only

Quintile of Index of Multiple Deprivation score	Type of diabetes <i>n</i> (%)		Total <i>n</i> (%)
	Type 1	Type 2	
1 (least deprived)	417 (18.3)	51 (10.2)	468 (16.9)
2	453 (19.9)	80 (16.0)	533 (19.2)
3	463 (20.3)	90 (18.0)	553 (19.9)
4	418 (18.3)	121 (24.2)	539 (19.4)
5 (most deprived)	467 (20.5)	153 (30.7)	620 (22.3)
Missing postcode	60 (2.6)	4 (0.8)	64 (2.3)
Total	2278 (100.0)	499 (100.0)	2777 (100.0)

Table 3.4: Women of Black, Asian and Other ethnic minority origin; quintiles of deprivation score according to type of diabetes, England only

Quintile of Index of Multiple Deprivation score	Type of diabetes <i>n</i> (%)		Total <i>n</i> (%)
	Type 1	Type 2	
1 (least deprived)	11 (4.7)	17 (3.4)	28 (3.8)
2	19 (8.1)	29 (5.8)	48 (6.5)
3	36 (15.3)	49 (9.8)	85 (11.5)
4	85 (36.0)	104 (20.7)	189 (25.6)
5 (most deprived)	84 (35.6)	298 (59.4)	382 (51.8)
Missing postcode	1 (0.4)	5 (1.0)	6 (0.8)
Total	236 (100.0)	502 (100.0)	738 (100.0)

much more pronounced in women with type 2 diabetes with nearly 60% of women of Black, Asian or Other ethnic minority origin with type 2 diabetes falling into the most deprived quintile.

3.3 Maternal deaths

There were five deaths of women within this cohort within 1 year of delivery. These deaths were identified by linkage with the CEMACH maternal death enquiry database.⁴ This linkage exercise was performed using date of delivery and a free text search for diabetes. All five of the women identified had type 1 diabetes. These five deaths consisted of one direct death (maternal collapse at 34 weeks of gestation due to possible pulmonary embolism) and four late maternal deaths: one death from ischaemic heart disease, one following mitral valve replacement, one secondary to sepsis following renal failure and one from malignant melanoma.

Previous reports on confidential enquiries into maternal deaths have only referenced women with diabetes if complications of diabetes itself were the cause of death.⁵ This report includes deaths from all causes and are thus higher. Further exploration of the causes and contributing factors to the deaths of these women will be examined and described in the next report on confidential enquiries into maternal deaths in the UK due to be published by CEMACH in late 2007.

3.4 Conclusion

Women with type 1 diabetes are different to women with type 2 diabetes with respect to certain demographic characteristics. Many of these are a reflection of the profile of the disease with type 2 diabetes traditionally being a disease of later life and being more common in people of Black, Asian or Other ethnic minority origin.

The most striking observation from the maternal demographic data was the strong association seen between deprivation and women with type 2 diabetes. This association was particularly seen in women of Black, Asian and Other ethnic minority origin.

It is possible that these data on deprivation are a reflection of the entire population of people with diabetes rather than specific to the maternity population with diabetes.

Targeting of services, however, will need to take account of the differing profiles of women with type 1 and type 2 diabetes.

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4 Standards of care for the mother

KEY FINDINGS

- There is evidence of poor preparation for pregnancy in women with diabetes.
- There is room for improvement in current standards of care during pregnancy.

4.1 Introduction

One of the aims of the diabetes project was to audit clinical standards of maternity and diabetes care for women with pre-gestational diabetes before, during and after pregnancy. A description of how these standards were derived is included in Chapter 1. The complete list of standards can be found in Appendix D.

It is important to note that assessment of clinical care had, of necessity, to be based on documentation in routine medical records. This meant that some standards could be evaluated only in part and this is detailed in the text where relevant. The results are based on the information provided on the 3808 pregnancies notified to CEMACH.

4.2 Standards of preconception care

4.2.1 Provision of preconception care

A preconception clinic should be run jointly by the adult diabetes service and the maternity service for women wishing to become pregnant.

[Diabetes NSF – illustrative service models;
www.publications.doh.gov.uk/nsf/diabetes/ch2/servicemodels/pregnancy.htm]

There was evidence that prepregnancy counselling was received by just over one-third (34.5%) of all women with pre-gestational diabetes (Table 4.1). Sixty-eight percent of these women received counselling at the adult diabetes clinic, 13% at a preconception clinic and 4% from the general practitioner. For 15% of women, the service providing counselling was not known.

Table 4.1: Documentation of prepregnancy glycaemic test and prepregnancy counselling

	Type 1 diabetes <i>n</i> (%) (<i>N</i> = 2767)	Type 2 diabetes <i>n</i> (%) (<i>N</i> = 1041)	All women <i>n</i> (%) (<i>N</i> = 3808)
Prepregnancy counselling documented ^a	1056 (38.2)	258 (24.8)	1314 (34.5)
Prepregnancy glycaemic test recorded	1108 (40.0)	306 (29.4)	1414 (37.1)

^a Excludes 21 women where the response was 'not known' or missing.

Similarly, just over one-third (37.1%) of women overall were reported as having had a pre-pregnancy measurement of long-term glycaemic control in the 6 months prior to pregnancy (Table 4.1). The women with type 2 diabetes were significantly less likely to have had this pre-pregnancy test ($P < 0.001$).

These findings suggest that the majority of women with pre-gestational diabetes were not adequately prepared for pregnancy. In Table 4.1, this is reflected in early pregnancy glycaemic control in these women (see section 4.4.1). The majority of women who did receive pre-pregnancy counselling did not do so in a multidisciplinary clinic, as advised by the standards of care.

4.2.2 Folic acid supplementation

Women with diabetes have an increased risk of fetal neural tube defects and should be offered pre-pregnancy folic acid supplements, continuing up to 12 weeks of gestation.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Less than half (39.2%) of women were documented in the medical records to have taken folic acid before their last menstrual period (Table 4.2). This is comparable with the general maternity population, where the uptake of folic acid before pregnancy is known to be 50% at best in the UK.¹ Uptake was markedly lower in women with type 2 diabetes compared with those with type 1 diabetes ($P < 0.001$) (Table 4.2).

Table 4.2: Documentation of preconception folic acid supplementation

Preconception folic acid supplementation	Type 1 diabetes <i>n</i> (%) (<i>N</i> = 2767)	Type 2 diabetes <i>n</i> (%) (<i>N</i> = 1041)	All women <i>n</i> (%) (<i>N</i> = 3808)
Taken	1187 (42.9)	306 (29.4)	1493 (39.2)
Not taken	1073 (38.8)	551 (52.9)	1624 (42.6)
Not known	507 (18.3)	184 (17.7)	691 (18.1)

Pre-pregnancy dietary advice by a health professional, duration of folic acid supplementation, the gestation at which it was discontinued and the dose taken, were not assessed in this study. However, women without diabetes who are at high risk of neural tube defects decrease this risk by the use of high-dose folic acid.² Women with pre-gestational diabetes are also in a high-risk category for neural tube defects. Current national guidelines recommend a higher dose (usually 5 mg) of folic acid for women at high risk.³⁻⁵ Both women and general practitioners should be aware of the importance of commencing folic acid before pregnancy in women with diabetes.

4.3 Standards of antenatal care

4.3.1 Dating the pregnancy and assessing for congenital malformations

All women with diabetes should be referred promptly for a first-trimester ultrasound scan to enable accurate dating of the pregnancy. They should all be offered a detailed anomaly ultrasound scan between 18 and 22 weeks and serial ultrasound scans during the third trimester to monitor fetal growth.

[Diabetes NSF – Intervention details;
www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

This standard is echoed by the National Institute for Clinical Excellence *Antenatal Care* guideline, which recommends that all pregnant women should be offered an ultrasound scan before 13 weeks of gestation to determine gestational age.⁶ This is particularly important for women with diabetes, where timely delivery is one of the main tenets of care.

A total of 2630 of 3586 women (73.3%) with an ongoing pregnancy at 13 weeks of gestation had a first-trimester dating scan. The reasons given for no first-trimester scan being performed (699 women) are shown in Table 4.3. The single largest contributing factor was units reporting a first trimester scan when in fact it had been performed after 13 weeks of gestation (median 14⁺³ weeks of gestation; interquartile range 13⁺³, 16⁺⁴). Early telephone referral from the general practitioner to a named contact within the specialist antenatal diabetes team may be useful to improve this aspect of care. An additional 163 women had a scan but the gestation was unknown with a not-known outcome in a further 94 women.

Table 4.3: Reasons for no first-trimester dating scan being performed (table contains information following categorisation of free text)

Reasons for no first-trimester scan	Number of women (%) (N = 699)
Reported to be done but actually performed after 13 weeks of gestation	546 (78.1)
Booked late for antenatal care	51 (7.3)
Woman declined or did not attend	9 (1.3)
Dating scan not considered necessary at unit	36 (5.2)
Reason not given or inadequately described	59 (8.4)

Units were asked if an anomaly scan was performed after 16 weeks of gestation: 3435 of 3552 women (96.7%) with an ongoing pregnancy had a detailed anomaly scan performed after this time, with no difference between women with type 1 and type 2 diabetes. A total of 117 women did not have an anomaly scan. Reasons for no anomaly scan were provided for 58 women. These included: anomaly scan performed before 16 weeks (17 women), late booking for antenatal care (nine women) and maternal choice (six women). A further 59 women had no documented reason for no having an anomaly scan.

4.3.2 Prophylactic antenatal steroids

If delivery is indicated before 34 weeks, administration of corticosteroids should be considered to prevent neonatal respiratory distress syndrome.

[Diabetes NSF – Intervention details;
www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

A total of 328 of 3474 women (9.4%) with a continuing pregnancy at 24 weeks of gestation delivered before 34 weeks of gestation. Thirty-five of these pregnancies resulted in a stillbirth. Of the remaining women, nearly three-quarters (70.3%) received a full course of antenatal steroid therapy (Table 4.4). The commonest reason for non-administration was delivery before the full course could be given. It was not possible to assess whether this was due to delays in administration, quick, spontaneous, preterm labour or expedited delivery for maternal or fetal reasons (Table 4.5). In a small group of women, diabetes was seen as a

Table 4.4: Women delivering at less than 34 weeks of gestation who received a full course of antenatal steroid therapy

Full course of antenatal steroids given	Number of women (%) (N = 293)
Yes	208 (70.3)
No	72 (24.6)
Not known	15 (5.1)

Table 4.5: Reasons given for non-administration of a full course of antenatal steroid therapy before 34 weeks of gestation (table contains information following categorisation of free text)

Reasons for non-administration of steroids before 34 weeks of gestation	Number of women (%) (N = 68)
Delivery prior to completion of full course	50 (73.5)
Health professionals concerned about effect of steroids on maternal glycaemic control	5 (7.4)
Declined by patient	1 (1.5)
Maternal infection	1 (1.5)
No reason given	11 (16.2)

contraindication to administration of antenatal steroids. This is not the case, although careful surveillance and adjustment of insulin regimens during this time is vital.

4.4 Standards of antenatal care of diabetes

4.4.1 Glycaemic control

Women should be encouraged and supported to monitor their blood glucose levels regularly and to adjust their insulin dosage, in order to maintain their blood glucose levels within the normal (non-diabetic) range. The aim should be for the woman to maintain her HbA_{1c} below 7.0%.

[Diabetes NSF – Intervention details;
www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

The information for this standard is evaluated in greater detail in Chapter 5. Less than one-third (28%) of women who had a glycosated haemoglobin (HbA_{1c}) measurement before pregnancy had a value of less than 7%. This proportion increased to 38% in the first trimester and at least 65% from 18 weeks onwards (Chapter 5). This reflects the poor level of preparation for pregnancy seen with regard to preconception care and folic acid supplementation.

4.4.2 Provision of glucagon kit

Hypoglycaemia should be discussed and glucagon made available with clear instructions on its use.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Just over one-quarter (26.5%) of all women with diabetes did not have a glucagon kit in the current pregnancy (Table 4.6). The reason for this was unclear in half of circumstances. Otherwise, ‘not hospital policy’ and ‘considered unnecessary by health professionals’ were cited most frequently and, in 5% of cases, women themselves declined the offer of a kit (Table 4.7). However, women with pre-gestational diabetes may develop ‘hypoglycaemia

Table 4.6: Provision of glucagon kit (percentages are the proportion of women in a category out of the total number of women with a valid response; i.e. excluding ‘not applicable’ and ‘missing’)

Provision of glucagon kit during pregnancy	Type 1 diabetes n (%) (N = 2767)	Type 2 diabetes n (%) (N = 1041)	All women n (%) (N = 3808)
Yes	918 (33.4)	280 (27.1)	1198 (31.7)
Already had glucagon kit	517 (18.8)	349 (33.8)	866 (22.9)
No	837 (30.4)	164 (15.9)	1001 (26.5)
Not known	480 (17.4)	239 (23.2)	719 (19.0)
Not applicable (early pregnancy loss)	12	9	21
Missing data	3	0	3

Table 4.7: Reasons given for not providing a glucagon kit (table contains information following categorisation of free text)

Reasons given for not providing a glucagon kit	Type 1 diabetes <i>n</i> (%) (<i>N</i> = 517)	Type 2 diabetes <i>n</i> (%) (<i>N</i> = 349)	All women <i>n</i> (%) (<i>N</i> = 866)
Not hospital policy	169 (32.7)	72 (20.6)	241 (27.8)
Not considered necessary by health professionals	24 (4.6)	49 (14.0)	73 (8.4)
Not considered necessary/declined by woman	27 (5.2)	12 (3.4)	39 (4.5)
Alternative hypoglycaemia interventions provided by unit	39 (7.5)	18 (5.2)	57 (6.6)
Advised to obtain kit from GP	4 (0.8)	3 (0.9)	7 (0.8)
Maternal lifestyle issues	4 (0.8)	7 (2.0)	11 (1.3)
Reason not given or inadequately described	250 (48.4)	188 (53.9)	438 (50.6)

unawareness' during pregnancy,⁷ and fatalities from hypoglycaemia have been documented in past reports into maternal deaths.^{8,9}

More women with type 2 diabetes (33.8%) did not receive a glucagon kit than women with type 1 diabetes (18.8%) ($P < 0.001$) (Table 4.6). The majority of women with type 2 diabetes will require to be changed on to insulin before or during pregnancy and many women with type 2 diabetes may be more vulnerable to hypoglycaemia because of specific cultural practices (e.g. fasting during religious festivals). It is important that the risks of hypoglycaemia are communicated to all women. Interpreting services should be used if required.

4.4.3 Detailed retinal assessment

A full retinal assessment should be undertaken in all women with pre-existing diabetes during the first trimester or at booking if this is later.

[Diabetes NSF – Intervention details;
www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Retinopathy may be exacerbated by pregnancy and assessment during the pregnancy is an essential aspect of care. A detailed retinal assessment was recorded at least once during pregnancy in 3039 of 3805 women (79.9%). This reflects the UK survey in 1994,¹⁰ where 81% of physicians reported carrying out retinal examinations during pregnancy, but falls short of the Scottish data, where 97% of pregnant women with type 1 diabetes had a detailed retinal assessment.¹¹ All diabetes maternity services should have robust processes in place to ensure that all women with diabetes have at least one detailed retinal assessment during pregnancy.³

4.5 Standards of care for labour and delivery

4.5.1 Mode and timing of delivery

The mode and timing of delivery should be determined on an individual basis, aiming to realise a spontaneous vaginal delivery by no later than 40 weeks of gestation if possible.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Less than one-quarter (24.4%) of women achieved a spontaneous vaginal delivery (Table 4.8). This was due to a high caesarean section rate of 67.4% (elective section accounting for 29.8% and emergency section for 37.6% of this rate).

The reasons for induction of labour and caesarean section, and the timing of delivery, are explored in greater detail in Chapter 6.

Table 4.8: Mode of delivery for women with pre-existing diabetes with continuing pregnancies after 24 weeks of gestation

Mode of delivery	All women: <i>n</i> (%) (<i>N</i> = 3474)
Vaginal:	1130 (32.5)
Spontaneous	847 (24.4)
Instrumental	268 (7.7)
Breech	15 (0.4)
Abdominal:	2340 (67.4)
Emergency caesarean	1305 (37.6)
Elective caesarean	1035 (29.8)
Not known	2 (0.1)
Missing	2 (0.1)

Sixty-eight of 3474 women (2.0%) (33 of 2524 [1.3%] of women with type 1 diabetes and 35 of 950 [3.7%] of women with type 2 diabetes) delivered after 40 completed weeks of gestation.

4.5.2 Intrapartum fetal heart rate monitoring

Continuous electronic fetal heart monitoring should be offered to all women with diabetes during labour and fetal blood sampling should be available if indicated.

[Diabetes NSF – Intervention details;
www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Of the 1832 women in labour with an ongoing pregnancy at 24 weeks of gestation, 1711 (93.4%) had continuous electronic fetal heart monitoring (CEFM). The availability of fetal blood sampling was not assessed. For seven women, electronic fetal heart rate monitoring was offered but declined by the woman. Of the small group of babies (121) who did not have CEFM in labour the majority (116 of 121; 95.9%) were at least 28 weeks of gestation. While the value of continuous intrapartum fetal monitoring in prematurity and maternal diabetes has not been specifically investigated, current national practice recommendations are that CEFM should be used in any situation where there is a higher risk of fetal compromise.¹²

4.5.3 Use of intravenous dextrose and insulin

Intravenous dextrose and insulin should be administered during labour and delivery following an agreed multidisciplinary protocol.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

The majority (86.3%) of women received an intravenous insulin and dextrose infusion during labour and delivery (Table 4.9). The small group who did not receive this when there was

Table 4.9: Intravenous infusion of insulin and dextrose at the time of delivery after 24 weeks of gestation (percentages are the proportion of women in the category out of the total number of women with a valid response; i.e. excluding 'missing')

	Type 1 diabetes <i>n</i> (%) (<i>N</i> = 2524)	Type 2 diabetes <i>n</i> (%) (<i>N</i> = 950)	All women <i>n</i> (%) (<i>N</i> = 3474)
Yes	2239 (88.8)	756 (79.6)	2995 (86.3)
No	152 (6.0)	137 (14.4)	289 (8.3)
No opportunity to give	90 (3.6)	39 (4.1)	129 (3.7)
Not known	41 (1.6)	18 (1.9)	59 (1.7)
Missing	2	0	2

opportunity to do so comprised a disproportionate number of women with type 2 diabetes. It is difficult to comment on this, as there are a small number of women with type 2 diabetes who are managed by diet alone during pregnancy and this may have contributed to the results.

4.6 Conclusion

Preconception care

- Nearly two-thirds of women did not have a record of prepregnancy counselling.
- Only one-third of women had a recorded assessment of glycaemic control in the 6 months prior to pregnancy.
- Less than two-fifths of all women were recorded as taking folic acid supplements before their last menstrual period.

These findings strongly suggest ineffective preconception targeting and fragmented service provision. Up to 40% of pregnancies in women with diabetes may be unplanned. Education about the importance of pregnancy preparation for all women with diabetes of reproductive age is an urgent need. Primary and secondary care services should aim to develop joint protocols based on national guidelines to ensure that all women with diabetes receive consistent preconception care of a high standard.

Care during pregnancy

- Fifteen percent of women in this cohort had their first dating scan after 13 weeks of gestation.
- One-fifth of women did not have a detailed retinal examination during pregnancy.
- One-fifth of women with type 1 diabetes and one-third of women with type 2 diabetes did not have a glucagon kit during pregnancy.
- Over one-quarter of women who delivered before 34 weeks of gestation did not receive a full course of antenatal steroids.

Women with diabetes are at high risk of complications during pregnancy. Early and prompt referral to secondary care series is essential. Maternity units need to ensure a strong multi-disciplinary team and the availability of guidelines that are evidence-based and agree with national recommendations.

Care during labour and delivery

- Only one-quarter of women achieved a spontaneous vaginal delivery.
- The majority of women received an intravenous infusion of insulin and dextrose during labour and delivery.
- The majority of babies had continuous electronic fetal monitoring in labour; only five (4.1%) babies who did not were less than 28 weeks of gestation.

The high caesarean section rate in diabetes is likely to be due, in part, to the conflict between achieving a vaginal delivery and concerns about adverse pregnancy outcome. This is discussed in Chapter 6.

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5 Glycaemic control and its measurement

KEY FINDINGS

- Only 37% of women with diabetes had a measurement of glucose control recorded in the 6 months prior to pregnancy.
- Women with type 2 diabetes and those from an ethnic minority were those most likely not to have had a documented glycaemic test by the end of the first trimester.
- Only 38% of women with a HbA_{1c} measured by 13 weeks of gestation had a value of less than 7%.

5.1 Introduction

It is accepted that good glycaemic control should be achieved prior to and during pregnancy, in order to reduce the risk of adverse outcomes. Elevated blood glucose levels in the periconception period are associated with higher rates of miscarriage and major congenital malformations.¹⁻³ The purpose of this chapter is to provide a description of the tests used to measure glycaemic control, their use in the planning and management of glycaemic control in pregnancy and an overview of levels of glycaemic control achieved at the different stages of pregnancy. Measurements of HbA_{1c} tests, or their equivalent, corresponding to the 6 months prior to pregnancy and to three points during the antenatal period (closest to 10 weeks, 20 weeks and 34 weeks of gestation), were requested as part of the data collection. For each measurement provided, the specified laboratory range for good control at the maternity unit was also requested.

5.2 Type of test used and recommended reference range

HbA_{1c} should be used to monitor long-term glycaemic control, as it is the only measure for which good data are available on the risk of subsequent diabetic complications.⁴ The vast majority of measurements in England, Wales and Northern Ireland were based on the HbA_{1c} test (Table 5.1). However, there were a few other types of test in use.

Table 5.1: Type of glycaemic control test by approximate gestation

	Prepregnancy (<i>n</i>) (<i>N</i> = 3808)	Less than 13+0 weeks (<i>n</i>) (<i>N</i> = 3808)	18–23+6 weeks (<i>n</i>) (<i>N</i> = 3539)	27+ weeks (<i>n</i>) (<i>N</i> = 3459)
HbA ₁	17	16	28	38
HbA _{1c}	1384	2597	2348	2655
Fructosamine	2	105	106	135
Other	0	11	10	9
Had test but type not recorded	11	3	4	10
No recorded test	2394	1076	1043	612

The data collection did not determine whether individual HbA_{1c} values were Diabetes Control and Complications Trial (DCCT) aligned. However, the majority of units in England, Wales and Northern Ireland (741) reported using a DCCT-aligned assay in 2002.

The specified local laboratory reference ranges for good control were variable, with 14.8% of tests having a reference range of less than 6%, 62.8% between 6.0% and 6.9%, 19.8% between 7.0% and 7.9% and 2.5% having a reference range of 8% or more. This may reflect some laboratories quoting a non-diabetic reference range (typically around 4.5–6.0%) with others possibly quoting a target range for good control in diabetes (usually 6.5–7.5%).

5.3 Glycaemic control tests

Only 1414 (37.1%) of all the women had a measurement of glucose control documented in the 6 months prior to pregnancy (Table 5.1). This implies that a significant proportion of women are entering pregnancy with little or no preparation. The proportion of reported tests rose to 71.7% by the end of the first trimester. These figures are dependent upon information being documented in the medical records and may therefore be an underestimate.

Table 5.2: Maternal characteristics of those who had a documented test of glycaemic control prepregnancy and by 13 weeks of gestation (percentages given are proportion of women for each demographic characteristic who had a documented test)

	Women (n)	Documented prepregnancy test n (%)	Documented test by 13 weeks n (%)
All women	3808	1414 (37.1)	2732 (71.7)
Diabetes type:			
Type 1	2767	1108 (40.0)	2076 (75.0)
Type 2	1041	306 (29.4)	656 (63.0)
Ethnicity:			
White	3059	1216 (39.8)	2287 (74.8)
Black	219	59 (26.9)	122 (55.7)
Asian	399	108 (27.1)	240 (60.2)
Chinese and Other	123	30 (24.4)	78 (63.4)
Not known	8	1 (12.5)	5 (62.5)
Age (years):			
<20	141	63 (44.7)	98 (69.5)
20–24	473	159 (33.6)	339 (71.7)
25–29	888	335 (37.7)	647 (72.9)
30–34	1277	489 (38.3)	944 (73.9)
35+	1009	365 (36.2)	695 (68.9)
Missing	20	3 (15.0)	9 (45.0)
Parity:			
Primiparous	1507	601 (39.9)	1114 (73.9)
Parous	2294	812 (35.4)	1615 (70.4)
Missing	7	1 (14.3)	3 (42.9)

The maternal characteristics associated with having had a glycaemic test prior to pregnancy and by 13 weeks of gestation are described in Table 5.2. Women with type 2 diabetes were less likely than women with type 1 diabetes to have had a documented prepregnancy test of glycaemic control ($P < 0.001$) (Table 5.2). They were also less likely to have had a test by 13 weeks in pregnancy ($P < 0.001$) (Table 5.2). This suggests that prepregnancy and early preparation for this group is less critically managed or these women are not accessing services.

Women from Black, Asian and Other ethnic minority groups were also significantly less likely to have had a documented prepregnancy test of glycaemic control ($P < 0.001$) (Table 5.2). This difference was also apparent in early pregnancy. This suggests social and cultural differences that need further evaluation.

Women aged 20–24 years at delivery were the least likely to have had a documented prepregnancy test of glycaemic control. However, women above 35 years of age were the least likely to have had a documented test of glycaemic control by 13 weeks. This aspect needs further investigation, as these women are more likely by age alone to be at risk of chromosomal abnormalities, which makes their apparent lack of prepregnancy preparation more surprising.

5.4 Glycaemic control values

During the preconception period and throughout pregnancy it is recommended that tests of long-term glycaemic control should be within the normal non-diabetic range; that is, HbA_{1c} below 7%.⁵ The values reported in this section are based on the women who had HbA_{1c} measurements recorded (see Table 5.1). If more than one value was provided within a given time period then the one which was taken at a gestation closest to the defined time period was included and the other values excluded. Values were also excluded if the timing of the test was outside the specified gestational range.

The median values of HbA_{1c} recorded prepregnancy and at subsequent stages during the pregnancy, according to the type of diabetes, are described in Table 5.3. The proportion of women with values of HbA_{1c} less than 7% at these different stages of pregnancy is also shown in Table 5.3.

Table 5.3: Values of HbA_{1c} prior to pregnancy and at various stages in pregnancy according to type of diabetes

	Prepregnancy	Weeks of gestation		
		<13 ⁺⁰	18–23 ⁺⁶	27 ⁺
All women:				
Median [IQR]	7.9 [6.9,9.1]	7.4 [6.5,8.4]	6.4 [5.7,7.1]	6.5 [5.9,7.3]
Result <7% n/N (%) ^a	382/1384 (27.6)	999/2597 (38.5)	1632/2348 (69.5)	1757/2655 (66.2)
Women with type 1 diabetes:				
Median [IQR]	7.9 [7.0,9.1]	7.5 [6.6,8.5]	6.5 [5.9,7.3]	6.6 [6.0,7.3]
Result <7% n/N (%) ^a	258/1081 (23.9)	700/1987 (35.2)	1148/1748 (65.7)	1232/1959 (62.9)
Women with type 2 diabetes:				
Median [IQR]	7.5 [6.3,9.2]	7.0 [6.1,8.1]	6.0 [5.5,6.7]	6.3 [5.75,6.9]
Result <7% n/N (%) ^a	124/303 (40.9)	299/610 (49.0)	484/601 (80.5)	525/696 (75.4)

^a Number of HbA_{1c} tests with a result below 7% as a proportion of all HbA_{1c} tests for that period; IQR = interquartile range.

The median value of HbA_{1c} prepregnancy for women with diabetes was 7.9%. The greatest reduction in HbA_{1c} values was seen by 20 weeks of gestation for women with either type 1 or type 2 diabetes.

Women with type 1 diabetes had higher values of HbA_{1c} throughout the various stages than those with type 2. Only 65.7% of women with type 1 diabetes achieved HbA_{1c} values below 7% by mid-pregnancy compared with 80.5% of women with type 2 diabetes (Table 5.3).

The median values of HbA_{1c}, before pregnancy and at subsequent stages during the pregnancy, according to the outcome of the pregnancy, are described in Table 5.4. The proportion of women with values of HbA_{1c} less than 7% at these different stages of pregnancy, according to the pregnancy outcome, is also shown in Table 5.4.

Table 5.4: Values of HbA_{1c} prior to pregnancy and at various stages in pregnancy according to pregnancy outcome

	Prepregnancy	Weeks of gestation		
		<13 ⁺⁰	18–23 ⁺⁶	27 ⁺
Malformations:				
Median [IQR]	8.35 [7.1,10.2]	7.9 [6.9,9.2]	6.8 [6.0,7.6]	6.6 [5.9,7.5]
Result <7% n/N (%) ^a	11/50 (22.0)	26/101 (25.7)	51/89 (57.3)	40/69 (58.0)
Normally formed stillbirths or neonatal deaths:				
Median [IQR]	8.8 [7.2,9.9]	7.8 [7.1,8.8]	7.2 [6.2,7.7]	7.2 [6.4,8.1]
Result <7% n/N (%) ^a	4/31 (12.9)	13/67 (19.4)	23/58 (39.7)	18/45 (40.0)
Normally formed and alive at 28 days:				
Median [IQR]	7.8 [6.8,9.0]	7.3 [6.4,8.3]	6.4 [5.7,7.1]	6.5 [5.9,7.2]
Result <7% n/N (%) ^a	341/1197 (28.5)	923/2291 (40.3)	1554/2192 (70.9)	1699/2540 (66.9)

^a Number of HbA_{1c} tests with a result below 7% as a proportion of all HbA_{1c} test for that period; IQR = interquartile range.

Higher prepregnancy HbA_{1c} values were observed in women who had a baby with a major congenital malformation and in those women who had a normally formed stillbirth or neonatal death. Both these groups of women had poorer glycaemic control throughout the pregnancy compared with women who had a normal baby. The poorest control was seen in those women who had a normally formed stillbirth or neonatal death, with less than half of this group achieving HbA_{1c} values of less than 7% at any stage in pregnancy. These observations support the aim of good glycaemic control periconceptionally and throughout pregnancy.

Good control as measured by HbA_{1c} is not, in itself, predictive of a good outcome. One-quarter of the women who had a baby with a congenital malformation had an HbA_{1c} value of less than 7% by 13 weeks of gestation. The value of HbA_{1c} is acting as a surrogate marker for glycaemic control and may not reflect fluctuations of glucose levels. Further research in this area is warranted.

5.5 Discussion

5.5.1 Tests

Only 37% of women with diabetes had a measurement of glucose control recorded in the 6 months prior to pregnancy. Although this figure is likely to be an underestimate, as it was dependent upon the quality of medical records, such a low figure clearly needs further review.

Women with type 2 diabetes and those from a Black, Asian or Other ethnic minority were those most likely not to have had a glycaemic test before pregnancy and by the end of the first trimester and the reasons for this require exploration. These findings are of particular concern in light of the increasing prevalence of type 2 diabetes in the young adult population.⁶

5.5.2 Glycaemic control

All groups of women with diabetes, regardless of type or ethnic group, should be entering pregnancy with substantially better glycaemic control than observed in this study. Only 38% of women with an HbA_{1c} value available by 13 weeks of gestation had a value of less than 7%. This does not compare well with other European countries, such as The Netherlands, where 75% of women with type 1 diabetes achieved HbA_{1c} of 7% or less in the first trimester.⁷ This suggests that considerable improvements in periconceptional glycaemic control can be achieved in the UK population.

The reduction in glycaemic values observed by around 20 weeks of gestation is, in part, physiological, as there is a reduction in levels due to the increased haematopoiesis and the presence of new unglycated red cells in the circulation in pregnancy.⁸ Health professionals and women may frequently be unaware of this pattern and may attribute this physiological shift to an improvement in control.

The relationship between poor periconceptional glycaemic control and poor perinatal outcome observed is consistent with other studies. Poor control during pregnancy was particularly notable in the women with normally formed stillbirths or neonatal deaths. These observations continue to support the policy of aiming to maintain the HbA_{1c} value at less than 7% before pregnancy and throughout pregnancy.

HbA_{1c} is a measurement of ‘average’ control of glucose over a period of time and does not measure the extent and frequency of fluctuations from normal glycaemia. Further research is needed in this area, to identify other aspects of control that may give further insight into how to further reduce adverse perinatal outcomes.

5.6 Conclusion

Nearly 15 years on from the St Vincent Declaration in 1989, babies born to women with diabetes in England, Wales and Northern Ireland continue to have high perinatal mortality rates and congenital anomaly rates (see Chapter 7). The importance of periconceptional glycaemic control was known by the 1980s and has been reinforced by randomised control evidence in 1996.⁹ Despite this, only a minority of women in this study achieved good glycaemic control by the end of the first trimester.

More work is required to elucidate how women with diabetes can commence pregnancy with improved glycaemic control.

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6 Characteristics of labour and delivery

KEY FINDINGS

- There is a high induction of labour rate (39%) and a high caesarean section rate (67%) in women with type 1 and type 2 diabetes.
- There is a high preterm delivery rate (36%), with the greatest single contributor to this rate being preterm caesarean section.
- The spontaneous preterm delivery rate is twice that in the general maternity population.

6.1 Introduction

The core principle of the National Service Framework for Diabetes is the achievement of a good outcome and experience of pregnancy and childbirth for women with pre-gestational diabetes.¹ With this principle in mind, this chapter provides a description of the events of labour and delivery for the 3474/3808 (91.2%) of women who had continuing pregnancies at 24 completed weeks of gestation and compares them with the experiences of the general maternity population. Judging how long to continue a pregnancy around term and how to deliver are key decisions for women with diabetes and health professionals. This chapter sets out to examine the indications for delivery and the timing of induction.

6.2 Onset of labour and mode of delivery

The events around childbirth for a woman with diabetes contrast significantly with those experienced by mothers in general. Table 6.1 shows that only a minority (18.0%) of women with diabetes went into spontaneous labour compared with 69% of mothers in general.²

Table 6.1: Onset of labour in women with pre-gestational diabetes compared with the general maternity population (percentages are proportion of women in category out of the total number of women with a valid response, i.e. excluding 'missing')

Onset of labour	Women with pre-gestational diabetes <i>n</i> (%) (<i>N</i> = 3474)	HES England and Wales 2002–03: <i>n</i> (%) ^a (<i>N</i> = 548 000)
Spontaneous	625(18.0)	378 120 (69)
Induced	1350 (38.9)	115 080 (21)
Elective or emergency caesarean section before labour	1483 (42.7)	60 280 (11)
Don't know	14 (0.4)	0 (0)
Missing	2	0

^a Source for national data: NHS Maternity Statistics England 2002–03, Bulletin 2004/10².

6.2.1 Induction of labour

Women with pre-gestational diabetes were nearly twice as likely to be induced, 38.9% (Table 6.1) compared with 21% in the general maternity population.² Induction for women

with diabetes was more likely to result in emergency caesarean section, 43.0%, compared with 19% for mothers in general.³

Routine induction because of maternal diabetes was the commonest indication for induction of labour, accounting for 654/1350 (48.4%) of all inductions and 36/253 (14.2%) of inductions before 37 completed weeks of gestation. The largest proportion of 'routine' inductions occurred between 38⁺⁰ and 38⁺⁶ completed weeks of pregnancy (Table 6.2).

Table 6.2: Indications for induction of labour in women with pre-gestational diabetes by gestation at induction (table contains information following categorisation of free text)

	Gestation at induction (completed weeks)				All inductions of labour n (%) (N = 1350)
	<37 weeks n (%) (N = 253)	37+0–37+6 n (%) (N = 406)	38+0–38+6 n (%) (N = 483)	39+ n (%) (N = 208)	
Routine for diabetes	36 (14.2)	194 (47.8)	293 (60.7)	131 (63.0)	654 (48.4)
General obstetric complications ^a	64 (25.3)	60 (14.8)	49 (10.1)	14 (6.7)	187 (13.9)
Presumed fetal compromise ^b	44 (17.4)	30 (7.4)	33 (6.8)	20 (9.6)	127 (9.4)
Large baby/polyhydramnios	16 (6.3)	49 (12.1)	41 (8.5)	9 (4.3)	115 (8.5)
Other clinical reason ^c	48 (19.0)	23 (5.7)	14 (2.9)	9 (4.3)	94 (7.0)
Premature rupture of membranes	29 (11.5)	24 (5.9)	31 (6.4)	10 (4.8)	94 (7.0)
Diabetes complication	8 (3.5)	11 (2.7)	8 (1.7)	1 (0.5)	28 (2.1)
Maternal request	2 (0.8)	0 (0.0)	4 (0.8)	1 (0.5)	7 (0.5)
Reason unknown or inadequately described	6 (2.4)	15 (3.7)	10 (2.1)	13 (6.3)	44 (3.3)

^a includes hypertensive disorder of pregnancy, antepartum haemorrhage, unstable lie and multiple pregnancy.
^b includes abnormal CTG, evidence of placental insufficiency, congenital malformation, rhesus isoimmunisation and obstetric cholestasis.
^c includes intrauterine death, medical and surgical complications in pregnancy and previous obstetric history.

6.2.2 Mode of delivery

The caesarean section rate was three times that for mothers in general, 67% compared with 22% (Table 6.3). Spontaneous vaginal delivery accounted for 24% of deliveries in women with diabetes compared with 67% in the general maternity population.

Table 6.3: Mode of delivery for women with pre-gestational diabetes with continuing pregnancies after 24 completed weeks of gestation (percentages are proportion of women in category out of the total number of women with a valid response, i.e. excluding 'missing')

Mode of delivery	Women with pre-gestational diabetes n (%) (N = 3474)	HES England & Wales 2002–03 n (%) (N = 548 000)
Vaginal	1130 (32.5)	427 440 (78)
Spontaneous vaginal	847 (24.4)	367 160 (67)
Instrumental vaginal	268 (7.7)	60 280 (11)
Vaginal breech	15 (0.4)	219 (0)
Abdominal	2340 (67.4)	12 056 (22)
Emergency caesarean	1305 (37.6)	71 240 (13)
Elective caesarean	1035 (29.8)	49 320 (9)
Not known	2 (0.1)	0 (0)
Missing data	2	0

^a Source for national data: NHS Maternity Statistics England 2002–03, Bulletin 2004/10².

6.2.3 Caesarean section

The indications for elective and emergency caesarean sections are shown in Table 6.4. Where more than one indication was given, a principal indication was assigned after consideration

Table 6.4: Indications for elective and emergency caesarean section in women with pre-gestational diabetes (table contains information following categorisation of free text)

Indication	Elective caesarean section: <i>n</i> (%) (<i>N</i> = 1035)	Emergency caesarean section: <i>n</i> (%) (<i>N</i> = 1305)	All caesarean section: <i>n</i> (%) (<i>N</i> = 2340)
Presumed fetal compromise ^a	52 (5.0)	610 (46.7)	662 (28.3)
Previous caesarean section	524 (50.6)	59 (4.5)	583 (24.9)
General obstetric complication ^b	162 (15.7)	170 (13.0)	332 (14.2)
Failure to progress in labour	0 (0.0)	326 (25.0)	326 (13.9)
Large baby	78 (7.5)	8 (0.6)	86 (3.7)
Other clinical reasons ^c	54 (5.2)	17 (1.3)	71 (3.0)
Diabetes complication	39 (3.8)	19 (1.5)	58 (2.5)
Maternal request	37 (3.6)	15 (1.1)	52 (2.2)
Routine for diabetes	45 (4.3)	0 (0.0)	45 (1.9)
Reason unknown or inadequately described	44 (4.3)	81 (6.2)	125 (5.3)

^a Includes abnormal CTG, evidence of placental insufficiency, cord prolapse, rhesus isoimmunisation and obstetric cholestasis.
^b includes hypertensive disorder of pregnancy, placenta praevia, antepartum haemorrhage, malpresentation, multiple pregnancy.
^c includes poor obstetric history, previous difficult delivery, intrauterine death, other medical and surgical complications.

of free text (see section 1.2.3). The indications for caesarean section performed at less than 37 completed weeks of gestation are shown in Table 6.5.

The two main contributing reasons for caesarean section overall were presumed fetal compromise (28.3% compared with 22% in the general maternity population) and previous caesarean section (24.9% compared with 14% in the general maternity population).³ However, caesarean section for failure to progress (13.9%) contributed less to the overall caesarean section rate than the rate for the general maternity population (21%).³

Table 6.5: Indications for preterm (less than 37 completed weeks) caesarean section (table contains information following categorisation of free text)

Indications for preterm (<37 completed weeks) caesarean section	Elective caesarean section <i>n</i> (%) (<i>N</i> = 342)	Emergency caesarean section <i>n</i> (%) (<i>N</i> = 598)	All caesarean sections <i>n</i> (%) (<i>N</i> = 940)
Presumed fetal compromise ^a	41 (12.0)	311 (52.0)	352 (37.4)
General obstetric complication ^b	59 (17.3)	126 (21.1)	185 (19.7)
Previous caesarean section	119 (34.8)	27 (4.5)	146 (15.5)
Failure to progress in labour	0 (0.0)	55 (9.2)	55 (5.9)
Large baby	34 (9.9)	3 (0.5)	37 (3.9)
Other clinical reasons ^c	21 (6.1)	8 (1.3)	29 (3.1)
Diabetes complication	34 (9.9)	18 (3.0)	52 (5.5)
Maternal request	7 (2.1)	6 (1.0)	13 (1.4)
Routine for diabetes	10 (2.9)	0 (0.0)	10 (1.1)
Reason unknown or inadequately describe	17 (5.0)	44 (7.4)	61 (6.5)

^a Includes abnormal CTG, evidence of placental insufficiency, cord prolapse, rhesus isoimmunisation and obstetric cholestasis.
^b includes hypertensive disorder of pregnancy, placenta praevia, antepartum haemorrhage, malpresentation, multiple pregnancy.
^c includes poor obstetric history, previous difficult delivery, intrauterine death, other medical and surgical complications.

Four percent of all caesarean sections and 2.4% of preterm sections were performed without any specific obstetric or medical indication (either ‘routine for diabetes’ or ‘maternal request’).

6.3 Preterm delivery

A total of 1243 (35.8%) of all women with diabetes had a preterm delivery before 37 completed weeks of gestation (Table 6.2). This compares with a rate of 7.4% for the general maternity population.²

The spontaneous preterm delivery rate (including preterm premature rupture of the membranes requiring induction) was 325/3474 (9.4%), nearly twice that of 4.7% in the general maternity population.²

Three-quarters of all preterm deliveries were iatrogenic and the majority of these were preterm caesarean sections (Table 6.6). Some 206/940 (21.9%) of these preterm caesarean sections were for previous caesarean section, large baby, maternal request or routine for maternal diabetes.

Table 6.6: Reasons for preterm delivery at less than 37 completed weeks of gestation in women with type 1 and type 2 diabetes (table contains information following categorisation of free text; percentages are proportion of women in category out of the total number of women with a valid response, i.e. excluding 'missing')

Reason for preterm delivery	All women <i>n</i> (%) (<i>N</i> = 1105)
Spontaneous	295 (26.7)
Spontaneous preterm labour	268 (24.3)
Induced after PPRM	27 (2.4)
iatrogenic ^a	803 (73.3)
Induction of labour for other reasons	181 (16.4)
Caesarean section	622 (56.3)
Not known	6 (0.5)
Missing data	1

^a Inductions for reasons other than preterm prelabour rupture of the membranes (PPROM), and all emergency and elective caesarean sections for women not in spontaneous preterm labour.

6.4 Discussion

It is currently accepted practice that all women with pre-gestational diabetes should be delivered by 40 weeks of gestation to minimise the risk of stillbirth.¹ Within this context, it is recommended that every effort should be made to avoid neonatal and maternal morbidity if at all possible, by careful consideration of timing and mode of delivery on a case-by-case basis.

The induction of labour rate was 39%, twice that in the general maternity population. Half of all inductions and 14% of preterm inductions were carried out as a routine policy due to maternal diabetes. There is a potentially higher risk of neonatal respiratory morbidity at earlier gestations, especially in women with suboptimal glycaemic control,⁴ and this should be taken into account when planning the timing of routine induction of labour for maternal diabetes.

The total caesarean section rate in the cohort was 67%, three times higher than the national average.³ The main contributors to this rate were emergency caesarean for presumed fetal compromise and repeat caesarean for previous caesarean section, both of which represented a higher percentage of the overall caesarean section rate than in the general maternity population. There is likely to be a constellation of factors behind these findings, such as the need to establish labour before 40 weeks of gestation, maternal pre-eclampsia and health professionals' concerns about fetal wellbeing, shoulder dystocia and uterine rupture. It is recognised that clinicians have a difficult task in evaluating the relative risks and benefits of alternative management approaches. The woman and her partner should be fully involved in the decision-making process.

The women in this study had a high (38%) emergency caesarean section rate. While the ratio of emergency to elective caesarean section in this study is the same as in the general maternity population, it is of concern that more than one-third of women, who are by definition, high

risk, undergo emergency surgical intervention. It is suggested that future research should be undertaken in this area to explore the possible underlying factors.

Four percent of all caesareans were performed without a specific medical or obstetric indication. This is likely to impact on these women's obstetric future, as caesarean section rates are trebled in women with a previous caesarean section and this is likely to be further compounded by diabetes.³ Vaginal delivery is the ideal mode of delivery for women with diabetes. Every effort should be made to minimise the potential for future morbidity by avoiding caesareans that are not clinically indicated.

There was a nearly five-fold increase in the preterm delivery rate compared with the general maternity population. This was mainly because of preterm caesarean sections performed before 37 completed weeks of gestation. While 37% of these procedures were performed for presumed fetal compromise, over one-fifth were carried out for elective indications (routine for diabetes, large baby, previous caesarean and maternal request). It is important to ensure that women with diabetes are not delivered prematurely unless there is an appropriate indication, in order to decrease the burden of neonatal morbidity, additional neonatal care and the emotional impact of separation.

6.5 Conclusions

Women with diabetes have a high rate of obstetric intervention, both before and during labour. This is likely to be due, in part, to the conflict faced by health professionals between achieving a normal vaginal delivery and concerns about adverse pregnancy outcome.

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7 Pregnancy outcomes

KEY FINDINGS

- The prevalence of major congenital anomalies was 41.8 per 1000 births.
- There was a three-fold increase in anomalies of the circulatory system and neural tube defects.
- Perinatal mortality was nearly four times higher in babies born to women with diabetes than in the general maternity population.
- There was no evidence of a difference in the perinatal mortality of babies born to women with type 1 or type 2 diabetes.

7.1 Introduction

A principal aim of the data collection was to provide national perinatal mortality rates for babies of women with pre-gestational diabetes and details on congenital anomalies in babies born to these women. This chapter provides these rates, together with a description of the pregnancy outcomes.

7.2 Outcomes

Of the 3808 pregnancies notified to this study, 3742 (98.3%) resulted in a singleton birth. There were 64 sets of twins and two sets of triplets, equating to a multiple maternity rate of 1.7%, which is similar to the multiple maternity rate of 1.5% seen in the general maternity population of England and Wales.¹

Of the 3808 pregnancies, there were 326 pregnancies delivering prior to 24 weeks. These comprised 64 legal abortions, 40 of which had an antenatally diagnosed congenital malformation; 261 *in utero* losses and two early neonatal deaths of a set of twins born at 20 weeks of gestation, both babies dying within an hour of birth. It is likely that there is an under-ascertainment of the actual number of pregnancies that ended before 24 weeks, as these women may not have accessed maternity services during the early stages of pregnancy.

The 3474 pregnancies (3414 singleton, 60 multiple) continuing at 24 weeks of gestation resulted in 87 stillbirths and 3449 live births.

7.3 Congenital anomalies

Suspected congenital anomalies in all live births, losses after 20 weeks and termination of pregnancy at any gestation were reviewed, as detailed in the methods section (Chapter 1). A total of 3591 offspring comprised 3451 live births, 87 stillbirths, 39 losses between 20 and 23 completed weeks of gestation and 15 terminations of pregnancy with a documented congenital anomaly. We compared observed confirmed congenital anomaly

numbers with expected figures calculated using the EUROCAT 2002 maternal age-specific data.²

A total of 197 major congenital anomalies was identified and confirmed in 148 offspring giving a prevalence of confirmed major anomalies of 41.8 per 1000 total births (live and still). This compares with 21 per 1000 births from the EUROCAT data for 2002/03.³ The most common confirmed anomalies were congenital heart disease and those of the limb, musculoskeletal and connective tissue (Table 7.1).

Table 7.1: Observed anomalies reported in 3591 offspring of women with diabetes

Anomaly group	Observed (expected) ^b (n)
One or more major anomaly of any type	144 (74.4)
Nervous system ^a	19 (8.4)
Neural tube defects	12 (3.5)
Remainder of central nervous system	7 (4.9)
Eye ^a	1 (1.5)
Ear ^a	0 (1.5)
Congenital heart disease ^a	60 (18.4)
Cleft lip/with or without palate ^a	1 (2.7)
Cleft palate ^a	3 (1.8)
Digestive system ^a	5 (5.3)
Internal genitourinary system ^a	14 (12.7)
External genitourinary system ^a	5 (5.2)
Limb, musculoskeletal and connective tissue ^a	24 (20.8)
Other non-chromosomal ^a	11 (-)
Chromosomal ^a	10 (16.8)
Trisomy 21	5
Other chromosomal	5

^a Multiple malformations within a group are counted only once. Total anomalies thus do not add up to 197.
^b Expected numbers in parentheses are based on data from EUROCAT 2002, adjusted for maternal age.

The number of offspring with one or more major anomalies was 35 (23.3% of offspring with anomalies). These were frequently multiple anomalies of the heart or limb, musculoskeletal and connective tissue.

7.4 Perinatal mortality rates

Mortality rates were calculated using 2536 births occurring in 1 calendar year (deliveries between 1 March 2002 to 28 February 2003), allowing comparisons with other national perinatal mortality rates. This, therefore, excludes those women booking before, but delivering after, February 2003 (see Chapter 1 for detailed methodology). We compared perinatal mortality rates with national mortality data from the CEMACH 2002 perinatal death notification database and the Office for National Statistics.

The neonatal and perinatal mortality rates include a set of twins born at 20 weeks of gestation who both died within 1 hour of birth. Crude mortality rates show no significant differences in the perinatal mortality rates in babies born to women with type 1 diabetes and type 2 diabetes ($P = 0.936$) (Table 7.2).

Maternal age-adjusted mortality rates showed significantly higher stillbirth, perinatal and neonatal mortality rates within this pregnancy cohort when compared to the population of England, Wales and Northern Ireland in 2002; 4.7, 3.8 and 2.6 times higher, respectively (Table 7.3).

Table 7.2: Stillbirth, perinatal and neonatal mortality in babies born to women with type 1 and type 2 diabetes in England, Wales and Northern Ireland, 01 March 2002–28 February 2003

	Type of diabetes			
	Type 1 (N = 1706)		Type 2 (N = 650)	
	Frequency (n)	Rate [95% CI]	Frequency (n)	Rate [95% CI]
Stillbirth ^a	44	25.8 [18.3–33.3]	19	29.2 [16.3–42.2]
Perinatal death ^a	54	31.7 [23.3–40.0]	21	32.3 [18.7–45.9]
Neonatal death ^b	16	9.6 [4.9–14.3]	6	9.5 [1.9–17.1]
^a Rate per 1000 live births + stillbirths. ^b Rate per 1000 live births.				

Table 7.3: Maternal age-adjusted stillbirth, perinatal and neonatal mortality in babies born to women with type 1 and type 2 diabetes in England, Wales and Northern Ireland, 01 March 2002–28 February 2003

	Women with diabetes (type 1 and 2)		National rate ^c (N = 620 841)	Rate ratio [95% CI]
	Frequency	Rate [95% CI]		
Stillbirth ^a	63	26.8 [19.8–33.8]	5.7	4.7 [3.7–6.0]
Perinatal death ^a	75	31.8 [24.2–39.4]	8.5	3.8 [3.0–4.7]
Neonatal death ^b	22	9.3 [5.2–13.3]	3.6	2.6 [1.7–3.9]
^a Rate per 1000 live births + stillbirths. ^b Rate per 1000 live births. ^c Source for national data – CEMACH 2005.				

7.5 Discussion

7.5.1 Congenital anomalies

There was a greater than expected number of anomalies reported in this pregnancy cohort. This is primarily due to a higher number of neural tube defects (3.4 times expected numbers) and congenital heart disease (3.3 times expected numbers).

The prevalence of anomalies reported in this study is substantially less than that reported by other UK-based studies, 94 per 1000 and 83 per 1000 births.^{4,5} This is most likely due to differences in inclusion criteria with this study including only major anomalies as per EUROCAT classifications. Other European studies which have considered only major anomalies showed a similar rate to this study, 50 per 1000 and 42 per 1000 births.^{6,7}

This study collected information on anomalies diagnosed up until day 28 of life. Defects identified after the neonatal period cannot therefore be enumerated. This means that the reported numbers of anomalies is likely to be an underestimate of the true number of anomalies seen in the offspring of these women.

Babies born to mother with diabetes are likely to be observed more closely following birth as they are at a high risk of other neonatal morbidities, such as respiratory distress and hypoglycaemia, than babies born to mothers without diabetes.⁸ It is therefore possible that some of the observed increase over expected numbers of cases of congenital heart disease is due to increased ascertainment in this group of babies following closer monitoring. However, this is unlikely to explain all of the increase and further work is required to understand the aetiology of these congenital anomalies with relation to diabetes.

Given the high numbers of neural tube defects seen in the offspring of these women it would appear necessary to specifically target these women with information concerning the benefit of folic acid supplementation prior to and during the first trimester of pregnancy.

7.5.2 Perinatal mortality rates

The stillbirth, neonatal and perinatal mortality rates reported for babies of this group of women are substantially higher than that observed in the general population with the stillbirth rate showing the greatest difference. Details on the causes of death of these babies were not available from this study but will be explored in the enquiry module of the CEMACH diabetes programme.

The national mortality rates in the offspring of women with type 1 diabetes presented here confirm previous regional studies conducted in the UK, which showed a stillbirth rate of 25.0 per 1000 and a perinatal mortality rate of 27.8 per 1000 live births and stillbirths.^{4,9} A recent population-based study in the Netherlands showed a perinatal mortality rate of 28 per 1000 live births and stillbirths in the type 1 diabetic population.¹⁰

Previous studies have reported perinatal mortality in the offspring of women with type 2 diabetes to be equivalent or higher than that seen to women with type 1 diabetes.^{11,12} There was no evidence from this study of a difference in the mortality rates of babies born to women with type 1 and type 2 diabetes. It is therefore important that services be targeted both to women with type 1 and with type 2 diabetes.

7.6 Conclusions

Prevalence of congenital anomalies and perinatal mortality rates remain high in the offspring of women with type 1 and type 2 diabetes. There is no evidence of a difference in perinatal mortality rates in the babies of women with type 2 diabetes when compared with women with type 1 diabetes. Further work is required to elucidate how women with diabetes, regardless of type, can be best enabled to improve the outcomes of their pregnancy.

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8 Description of the babies

KEY FINDINGS

- Over one-third of all babies were born prematurely.
- Over half of singleton babies were over the 90th centile for birth weight adjusted for gestation, sex of baby and parity of mother.
- There was an increased incidence of both shoulder dystocia and Erb's palsy.
- Over half of all babies were admitted to a neonatal unit.

8.1 Introduction

Babies born to women with diabetes are at increased risk of adverse neonatal outcomes, including neonatal death, prematurity, hypoglycaemia and respiratory disorders, and also experience a higher prevalence of macrosomia compared with the general population.^{1–5} They also have an associated increased risk of shoulder dystocia and birth trauma.⁶ This chapter provides a description of the babies born to women in this study and some of these adverse outcomes. No specific questions were included in the data collection tool to look specifically at neonatal hypoglycaemia or respiratory disorders. Findings relating to standards of care for the babies are described in Chapter 9.

8.2 Sex of the baby

Sex was recorded in 3528/3538 (99.7%) of all live births and stillbirths. The sex ratio in the study population (male : female) was 1.03 compared with 1.05 in the general population.⁷

8.3 Gestation

This section includes information on all births after 24 weeks of gestation, comprising 3449 live births and 87 stillbirths. A total of 1296/3536 (36.7%) babies delivered preterm (less than 37 completed weeks of gestation) (Table 8.1) compared to a preterm delivery rate of only 7.3% in England and Wales for 2002–03.⁸ The majority of these preterm babies were

Table 8.1: Gestation at delivery by outcome (percentages are proportion of babies in each category out of the total number of babies with a valid response, i.e. excluding 'not applicable' and 'missing')

Gestation at delivery (completed weeks)	Frequency: <i>n</i> (%)			
	Alive at 28 days (<i>N</i> = 3423)	Stillbirth (<i>N</i> = 87)	Neonatal death (<i>N</i> = 26)	Total (<i>N</i> = 3536)
24–27	19 (0.6)	15 (17.2)	10 (38.5)	44 (1.2)
28–31	115 (3.4)	12 (13.8)	2 (7.7)	129 (3.7)
32–36	1077 (31.5)	36 (41.4)	10 (38.5)	1123 (31.8)
37–41	2210 (64.6)	24 (27.6)	4 (15.4)	2238 (63.3)
42+	2 (0.1)	0 (0.0)	0 (0.0)	2 (0.1)

born between 32+0 and 36+6 weeks of gestation. Twenty-six liveborn babies born after 24 completed weeks subsequently died in the neonatal period, of which 22 were born preterm. The details of these deaths, including cause of death, were not available from this dataset but will be examined as part of the enquiry module of the CEMACH diabetes project.

8.4 Birth weight

Macrosomia (birth weight 4000 g and over) is a recognised complication for babies of women with diabetes. In this study population, 714/3405 singleton births (21.0%) with a known birth weight had a birth weight of 4000 g or more compared with only 11.0% of singleton births nationally in 2002–03.⁸ A total of 201 (5.7%) singleton babies were classified as severely macrosomic (birth weight 4500 g or over).

There was no significant difference between the birthweight distributions of singleton babies born to women with type 1 diabetes compared with that of singleton babies born to women with type 2 diabetes ($P = 0.308$) (Figure 8.1).

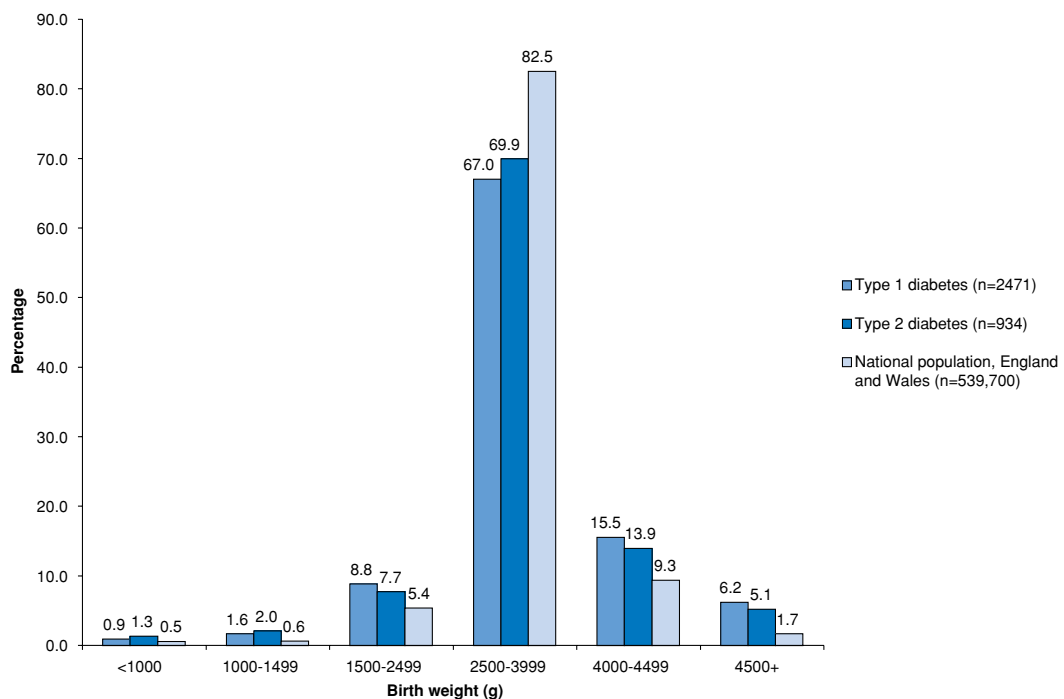


Figure 8.1: Birthweight distribution of singleton babies by type of diabetes compared with national population

Birthweight centiles were applied to all singleton births with a known birth weight, adjusting for the sex of baby, parity of mother and gestation at delivery, based on the population of Aberdeen in the 1980s.⁹ Of the 3251 babies for whom it was possible to apply a birthweight centile, 1679 (51.7%) were at or above the 90th centile for gestational age. Only 84 babies (2.6%) were below the tenth centile for gestational age.

8.5 Shoulder dystocia and birth trauma

8.5.1 Shoulder dystocia

Shoulder dystocia was documented in 89 of the 1124 singleton vaginal deliveries (7.9%). This compares with 3% in large regional published data.¹⁰ The incidence of shoulder dystocia

by birth weight is shown in Table 8.2. For babies with a birth weight between 4250 g and 4499 g the incidence of shoulder dystocia was 25.0% compared with published figures of only 9.1% in non-diabetic pregnancies in this weight range.¹⁰

Table 8.2: Shoulder dystocia in babies born by vaginal delivery

Birth weight (g)	Shoulder dystocia/total vaginal deliveries n/N (%)
<2500	1/107 (0.9)
2500–3999	40/845 (4.7)
4000–4249	18/82 (22.0)
4250–4499	12/48 (25.0)
4500+	18/42 (42.9)

When gestation-specific birthweight centiles were applied as before, 75 (84.3%) of all babies who had shoulder dystocia were at or above the 90th centile for gestational age.

These incidences may be influenced by increased reporting of shoulder dystocia when the babies are anticipated to be large.

8.5.2 Erb's palsy

There were 16 cases of Erb's palsy reported. This gives an incidence of Erb's palsy in babies born to women with pre-gestational diabetes of 4.5 per 1000 births. This incidence of Erb's palsy is more than ten-fold greater than that for the general population of the United Kingdom reported in a study conducted by the British Paediatric Surveillance Unit in 1999, which gave an incidence of Erb's palsy of 0.42 per 1000 live births.¹¹

Twelve of these babies were delivered vaginally with the remaining four delivered by caesarean section (two elective; two emergency). Eight of the babies were also recorded as having been delivered with shoulder dystocia. This gives a figure of 66.7% of vaginally delivered babies with Erb's palsy associated with shoulder dystocia. This compares with figures of 56% and 64% of all cases of brachial plexus injury recorded in two studies of births in which shoulder dystocia also occurred.^{10,11}

8.5.3 Other birth trauma

Fractures were reported in eight babies – fractured humerus in five babies (four with associated shoulder dystocia) and three babies with fractured clavicles (one with associated Erb's palsy).

An additional 60 babies were documented as having some other form of birth trauma with the most common being bruising (27/60) and markings associated with assisted vaginal delivery (13/60).

8.6 Condition of babies at birth

Apgar scores at 5 minutes were known for 3421/3451 (99.2%) live births. Median Apgar score was 9 (Interquartile range 9, 10) and 2.6% of all live births had an Apgar score of less than 7 at 5 minutes. This compares with 0.76% in a large population-based register using the same cutoff point.¹²

8.7 Neonatal admission

Information was recorded on admission at any time after delivery to a neonatal unit for all babies. The admission pattern for infants of mothers with pre-gestational diabetes is shown in Table 8.3. Of the 3451 live births, 1945 (56.4%) were admitted to a neonatal unit. The median length of stay for all babies who received care away from their mothers was 4 days (interquartile range 2, 10).

Table 8.3: Neonatal admission at any time following delivery, by gestation at delivery (percentages are proportion of babies in category out of the total number of babies with a valid response, i.e. excluding 'not applicable' and 'missing')

Type of neonatal care	Gestation at delivery, completed weeks n (%)			
	<32 (N = 148)	32–36 (N = 1087)	37+ (N = 2216)	Total (N = 3451)
Special care	19 (13.3)	474 (43.7)	723 (32.6)	1216 (35.3)
High-dependency care	53 (37.1)	220 (20.3)	171 (7.7)	444 (12.9)
Intensive care	68 (47.6)	111 (10.2)	54 (2.4)	233 (6.8)
Other specialist care	3 (2.1)	12 (1.1)	37 (1.7)	52 (1.5)
Postnatal ward normal care with mother	0 (0.0)	258 (23.8)	1217 (54.9)	1475 (42.8)
Not known	0 (0.0)	9 (0.8)	14 (0.6)	23 (0.7)
Not applicable (early neonatal death)	5	2	0	7
Missing	0	1	0	1

Most preterm infants (less than 37 completed weeks of gestation) received some form of neonatal care (special care, high dependency care, intensive care or other specialist care), 960/1235 (77.7%).

One-third of all term infants (37 weeks of gestation and above) were admitted to a neonatal unit for special care compared with 10% in the general population.¹³ Reasons for these term babies' admissions can be found in Chapter 9. A higher proportion of term babies born to mothers with type 1 diabetes were admitted to a neonatal unit compared to those of mothers with type 2 diabetes (rate ratio 1.18; 95% CI 1.05–1.31; $P = 0.003$).

8.8 Conclusion

Over one-third of all babies in this study were born preterm, almost five times the rate seen in the general maternity population. This is, in part, linked to an increased incidence of induced preterm delivery (see Chapter 6).

Women with diabetes gave birth to larger babies than the general maternity population of England, Wales and Northern Ireland. Half of the babies were above the 90th centile for birth weight adjusted for gestation at delivery, sex of baby and parity of mother. This was associated with a two-fold increase in shoulder dystocia and a ten-fold increase in Erb's palsy.

Over half of all babies of women with diabetes were admitted to a neonatal unit. This high incidence of admission may be partly explained by the high rate of prematurity among these babies. However, one-third of all term babies were also admitted to a neonatal unit for special care (more so in women with type 2 diabetes), three times the national average (see Chapter 9).

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9 Standards of care for the babies

KEY FINDINGS

- The vast majority of babies (95%) were born in a maternity unit with facilities and staff for the resuscitation and stabilisation of babies.
- One-third of term babies were admitted to a neonatal unit for special care. The results suggest that not all of these admissions were clinically indicated.
- Fifty-three percent of women intended to breastfeed; this compares with an initial breastfeeding rate of 69% in the general population.

9.1 Introduction

This chapter relates to standards of care for the babies of women with pre-gestational diabetes. It is important to note that assessment of clinical care in this project had, of necessity, to be based on documentation in the medical records. This meant that some standards could be evaluated in part only. This is noted in the text where relevant.

9.2 Facilities at delivery

Labour and delivery should be undertaken in a maternity unit with facilities for the resuscitation and stabilisation of babies and with personnel skilled in advanced resuscitation immediately available on a 24-hour basis.

[SIGN guidelines No. 9]

[Diabetes NSF – Intervention details;

www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Concurrent with this cohort project, CEMACH also undertook a survey of the maternity services of organisations expected to be providing maternity care for women with diabetes in England, Wales and Northern Ireland.¹ The hospital of delivery was linked to the data from this organisation survey to assess the level of neonatal care available.¹ Of the 3451 live births, 9.4% (325/3451) could not be assessed because there was no organisation survey response for the unit of delivery. Ninety-five percent (2983/3126) of the remaining babies were born in a unit which had facilities to provide neonatal care above special care, with at least some form of high-dependency and short-term intensive care.

9.3 Admission to a neonatal unit and subsequent mother/baby separation

All babies should remain with their mothers during the neonatal period unless there is a specific medical indication for admission to a neonatal unit.

[SIGN guidelines No. 9]

[Diabetes NSF – Intervention details;

www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

The admission pattern for infants of mothers with diabetes is detailed in Chapter 8. Of the 3451 live births for which information was available, 1945 (56.4%) were admitted to a neonatal unit for intensive, high-dependency or special care. Thirty-five percent (1216/3451) of all live births were admitted for special care only.

Term infants (delivered at 37 completed weeks of gestation and over) are, in general, unlikely to need care in a neonatal unit. In the term baby population, the admission rate in the UK is generally below 10%.² When term babies or even babies with mild prematurity (that is, those delivered at 35–36 completed weeks of gestation) need admission for special care, some UK hospitals provide alternative models of care, such as mother and baby rooming-in facilities called transitional care units.^{3,4}

In order to explore the pattern of admission/separation of these babies, we stratified admissions by gestation at delivery of less than 35 completed weeks, 35–36 completed weeks and 37 completed weeks and over. The types of neonatal care for which the baby was managed separately from the mother (special, high-dependency or intensive care) were also categorised. The results for babies delivering at or after 35 completed weeks of gestation is shown in Table 9.1. A high proportion, 32.6% (723/2216) of term infants of mothers with diabetes was admitted for special care. Median stay/separation time for these term infants was 2 days, (interquartile range 1–4). Forty-four percent of infants with mild prematurity (35–36 completed weeks of gestation) were also admitted for special care. The median stay/separation for these infants was 4 days (interquartile range 2–7).

Table 9.1: Type of neonatal care received by gestation at delivery of 35 completed weeks and over

Type of neonatal care	Gestation at delivery, completed weeks <i>n</i> (%)		Total <i>n</i> (%) (<i>N</i> = 2960)
	35–36 (<i>N</i> = 744)	37+ (<i>N</i> = 2216)	
Special care	324 (43.5)	723 (32.6)	1047 (35.4)
High dependency	118 (15.9)	171 (7.7)	289 (9.8)
Intensive care	48 (6.5)	54 (2.4)	102 (3.4)
Other	10 (1.3)	37 (1.7)	47 (1.6)
Usual postnatal ward care	237 (31.9)	1217 (54.9)	1454 (49.1)
Not known	7 (0.9)	14 (0.6)	21 (0.7)

The reasons for admission to a neonatal unit for special care documented in the data collection tool in the term population of infants of mothers with diabetes were categorised (see Chapter 1 for methodology) (Table 9.2). A higher proportion of term babies born to mothers with type 1 diabetes was admitted to a neonatal unit compared with those of mothers with type 2 diabetes (rate ratio 1.18; 95% CI 1.05–1.31; *P* = 0.003) (see Chapter 8). Nevertheless, the reasons for special care admissions were the same for term babies of mothers with type 1 and type 2 diabetes.

Nearly one-third of term infant admissions (31.1%; (225/723) (group III) were unlikely to be avoidable (hypoglycaemia needing treatment, respiratory symptoms, cyanotic episodes, suspected or confirmed sepsis, feeding difficulties, other medical conditions and ill mother/adoption process).

The results suggest that almost two-thirds of the admissions could have been avoided or potentially avoided. Two main categories emerged:

- Routine admission (group I): one-quarter of admissions occurred for babies with no apparent adverse clinical condition. Reasons provided were: (a) because they were categorised by the hospital staff as “infants of diabetic mothers”; (b) because there was a hospital policy to admit them, regardless of their clinical condition or (c) because of

Table 9.2: Infants of mothers with pre-gestational diabetes delivering at 37 completed weeks of gestation and over: documented reasons for admission to a neonatal unit for special care (table contains information following categorisation of free text)

Reason for admission	All Infants n (%) (N = 723)
Group I	185 (25.6)
"Infant of diabetic mother"	62 (8.6)
Observation/monitoring alone	66 (9.1)
Routine/hospital guideline	57 (7.9)
Group II	300 (41.5)
Isolated documented blood glucose <2.6 mmol/l	45 (6.2)
Isolated non documented hypoglycaemia	228 (31.5)
Hypoglycaemia with hypothermia	11 (1.5)
Hypoglycaemia with jaundice	8 (1.1)
No mother–baby facilities/cots available	8 (1.1)
Group III	225 (31.1)
Hypoglycaemia needing treatment (including symptomatic)	27 (3.7)
Ill mother/ adoption process	3 (0.4)
Other medical conditions (i.e. cardiac, abstinence syndrome)	64 (8.9)
"Dusky"/cyanotic episode	8 (1.1)
Feeding difficulties	25 (3.5)
Respiratory symptoms	80 (11.1)
Suspected or confirmed sepsis	18 (2.5)
Misclassified (i.e. prematurity, transitional care)	6 (0.8)
Not known	8 (1.1)

observation/monitoring alone (25.6%; 185/723). These babies may have potentially been managed on a postnatal ward with adequate clinical support.

- Forty-one percent (300/723) of admissions to a neonatal unit for special care (group II) occurred for babies with minor clinical conditions such as isolated hypoglycaemia, cold or jaundiced hypoglycaemia. These babies may have potentially been managed with alternative strategies to routine admissions such as transitional care facilities.^{3,4}

Overall, these results must be interpreted with some caution since the categorisation was made from the 'reason for admission' free text entered by local data collectors into the cohort pro forma. The results from the on-going diabetes enquiry process where panels have direct access to the medical records may help ascertain further these descriptive findings.

9.4 Infant feeding

9.4.1 Timing of first feed

Babies born to women with diabetes should be fed as soon as possible after birth and all should receive their first feed within 4 hours of birth, unless contraindicated for medical reasons.

[SIGN guidelines No. 9]

[Diabetes NSF – Intervention details;

www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

The median time to first feed was 60 minutes, interquartile range 41–104.

Table 9.3 shows 40.1% of all infants were fed within 1 hour and 79.5% by 4 hours. Looking specifically at the population of term infants (37 completed weeks of gestation and over) who should be fed early unless a specific clinical condition requires that the first feed is delayed, eight out of ten babies were fed within the first 4 hours, as specified in the standard.

Table 9.3: Time to first feed according to gestation at birth (percentages are proportion of babies in each category out of the total number of babies with a valid response, i.e. excluding 'not applicable' and 'missing')

Time to first feed (hours)	Gestation at delivery, completed week: <i>n</i> (%)		All babies (<i>N</i> = 3451)
	<37 (<i>N</i> = 1235)	37+ (<i>N</i> = 2216)	
1	351 (28.4)	1031 (46.5)	1382 (40.1)
4	635 (51.5)	1837 (87.7)	2717 (78.8)
24	774 (62.7)	1943 (87.7)	2717 (78.8)
No feed in first 24 hours	320 (25.9)	72 (3.2)	392 (11.4)
Not known	140 (11.3)	201 (9.1)	341 (9.9)
Missing	1	0	1

9.4.2 Breastfeeding

Breastfeeding is recommended but all mothers should be supported in the feeding method of their choice.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

[Diabetes NSF – Intervention details;

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Breast milk appears to promote ketogenesis.⁵ It should be therefore be the food of choice for babies of mothers with diabetes who are at risk of hypoketonaemic hypoglycaemia.⁶ Exclusive breastfeeding was the choice at birth for 53% (1762/3342) of all women in this cohort (Table 9.4). The proportion of women intending to breastfeed was similar for mothers of both preterm and term babies (Table 9.4) and was less than the most recently published UK general population prevalence of breastfeeding of 69%.⁷

Table 9.4: Chosen method of feeding at delivery: intention to breastfeed (percentages are proportion of babies in each category out of the total number of babies with a valid response, i.e. excluding 'not applicable' and 'missing')

Feeding method	Gestation at delivery, completed weeks <i>n</i> (%)		All babies <i>n</i> (%) (<i>N</i> = 3451)
	<37 (<i>N</i> = 1235)	37+ (<i>N</i> = 2216)	
Breastfeeding	584 (48.7)	1178 (55.0)	1762 (52.7)
Formula milk	466 (38.9)	728 (34.0)	1194 (35.7)
Breastfeeding and formula milk	100 (8.3)	197 (9.2)	297 (8.9)
Not known	49 (4.1)	40 (1.9)	88 (2.7)
Missing	1	0	1
Excluded	35	73	108

At 28 days after birth, the proportion of exclusively breastfed babies was 23.8%, half the proportion who had intended to breastfeed at delivery (Table 9.5). When babies who were

Table 9.5: Feeding method at 28 days (percentages are proportion of babies in each category out of the total number of babies with a valid response, i.e. excluding 'not applicable' and 'missing')

Feeding method	Gestation at delivery, completed weeks <i>n</i> (%)		All babies <i>n</i> (%) (<i>N</i> = 3451)
	<37 (<i>N</i> = 1235)	37+ (<i>N</i> = 2216)	
Breastfeeding	224 (18.5)	591 (26.7)	815 (23.8)
Formula milk	634 (52.4)	1013 (45.8)	1647 (48.1)
Breastfeeding and formula milk	218 (18.0)	344 (15.6)	562 (16.4)
Other	11 (0.9)	3 (0.1)	14 (0.4)
Not known	123 (10.2)	260 (11.8)	383 (11.2)
Not applicable (neonatal death)	24	4	28
Missing	1	1	2

both breast and bottle fed were identified, the proportion still having breast milk at 28 days after birth was 40.3%, a 13% drop from breastfeeding intent at the time of birth. This was comparable to the prevalence of breastfeeding at 6 weeks of 42% in UK.⁷ The proportion of preterm babies still exclusively breastfed at 1 month of age was lower (18.5%) than for term babies (26.7%).

9.4.3 Management of feeding

Interventions should be guided by blood glucose level and clinical assessment.

[CEMACH Diabetes Multidisciplinary Resource]

The main reason for giving term infants of mothers with diabetes supplemental milk or glucose was a history of low blood glucose level alone (36.7%) (Table 9.6). Nine percent of term babies had this treatment because of routine local practice and this may affect normal glucose regulation in healthy term babies.⁸ Accepted best practice for intervention in normal term infants comprises the following:

- persistent hypoglycaemia
- persistent hypoglycaemia after a feed
- clinical signs of hypoglycaemia
- both low blood glucose and clinical signs of hypoglycaemia.⁹

However, the results must be interpreted with caution because of the large number of “not known” responses (Table 9.6).

Table 9.6: Reasons for giving supplemental milk or glucose in first 24 hours (table contains information following categorisation of free text; percentages are proportion of babies in each category out of the total number of babies with a valid response, i.e. excluding ‘not applicable’ and ‘missing’)

Reason for supplementing	Gestation at delivery, completed weeks <i>n</i> (%)		
	<37 (<i>N</i> = 1235)	37+ (<i>N</i> = 2216)	All babies <i>n</i> (%) (<i>N</i> = 3451)
Low blood glucose	435 (35.8)	812 (37.2)	1247 (36.7)
Clinical signs of hypoglycaemia	31 (2.6)	30 (1.4)	61 (1.8)
Both low blood glucose and clinical signs of hypoglycaemia	125 (10.3)	127 (5.8)	252 (7.4)
Routine practice	168 (13.8)	152 (7.0)	320 (9.4)
Other reasons	170 (14.0)	252 (11.5)	422 (12.4)
Not known	285 (23.5)	811 (37.1)	1096 (32.3)
Not applicable (early neonatal death)	11	4	15
Missing	10	28	38

9.5 Blood glucose testing

9.5.1 Early blood glucose testing

Babies of mothers with diabetes should have a test of blood glucose concentration by 4–6 hours of age, before a feed.

[CEMACH Diabetes Multidisciplinary Resource]

Diabetes NSF – Intervention details;

www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm

Infants of mothers with diabetes display transient hyperinsulinism but, provided that hypoglycaemia is treated appropriately, most studies have found that their neurodevelopmental

outcome was similar to that of babies born to women without diabetes.⁶ These infants therefore need reliable blood glucose testing.

Median time to first blood glucose measurement was 60 minutes (interquartile range 30–120); 83.2 % of all infants of mothers with diabetes had a blood glucose test within the first 6 hours of life (Table 9.7). This is mainly within standards and accepted best practice.⁸ Nevertheless, a median time to first blood glucose testing of 1 hour may also suggest that testing was often too early. Testing too early may simply uncover the physiological fall in blood glucose after birth, leading to unnecessary intervention.

Table 9.7: Age at first blood glucose test

First test (hours)	Gestation at delivery, completed weeks <i>n</i> (%)		All babies (<i>N</i> = 3451)
	<37 (<i>N</i> = 1235)	37+ (<i>N</i> = 2216)	
1	660 (53.4)	972 (43.9)	1632 (47.3)
4	981 (79.4)	1726 (77.9)	2707 (78.4)
6	1019 (82.5)	1852 (83.6)	2871 (83.2)
>6	33 (2.7)	85 (3.8)	118 (3.4)
Not known	183 (14.8)	279 (12.6)	462 (13.4)

9.5.2 Blood glucose testing method

The diagnosis of hypoglycaemia should be made using a ward-based glucose electrode or laboratory method and not by reagent strip testing.

[CEMACH Diabetes Multidisciplinary Resource]

[SIGN guidelines No. 9]

Glucose reagent strips may not be reliable^{8,10} and are now regarded as contraindicated in neonates.¹¹ At least one reliable laboratory value should be obtained when considering the diagnosis of hypoglycaemia.⁸ The suitability for the detection of neonatal hypoglycaemia of portable glucose photometer such as HaemoCue (HaemoCue®, Angelholm, Sweden) is not universally accepted;^{12–14} however, if used as screen, a suspect/abnormal result value should at least be followed by laboratory confirmation. More accurate laboratory or ward-based glucose electrode measurements are therefore preferable among babies at risk.⁶ Reagent strips were used in one-third of babies. Only 29.3% (362/1253) of preterm infants and 25.0% (555/2216) of term babies were monitored using these optimal testing methods (Table 9.8).^{8,10} These results must also be interpreted with caution because of the number of missing values and

Table 9.8: Method used to test baby's blood glucose in first 24 hours (percentages are proportion of babies in each category out of the total number of babies with a valid response, i.e. excluding 'not applicable' and 'missing')

Method	Gestation at delivery, completed weeks: <i>n</i> (%)		All babies <i>n</i> (%) (<i>N</i> = 3451)
	<37 (<i>N</i> = 1235)	37+ (<i>N</i> = 2216)	
Optimal tests:			
Laboratory-based method	125 (10.2)	116 (5.2)	241 (7.0)
Glucose electrode	237 (19.4)	439 (19.8)	676 (19.7)
Suboptimal tests:			
Reagent strip	435 (35.6)	780 (35.2)	1215 (35.3)
Haemocue	329 (26.9)	722 (32.6)	1051 (30.6)
Not known	97 (7.9)	158 (7.1)	255 (7.4)
Not applicable (early neonatal death)	8	1	9
Missing	4	0	4

of the reported difficulties in categorising the blood glucose testing method or combined methods (such as HaemoCue and laboratory) used from the medical records.

9.6 Conclusions on neonatal standards for infants of mothers with diabetes

Some neonatal standards were met:

- The vast majority (95%) of the babies were born in a maternity unit with facilities and staff for neonatal resuscitation.
- Most term (83%) babies were fed shortly after birth and within 4 hours of birth.
- Most babies (83%) had a blood glucose measurement within 6 hours after birth.

Some aspects of clinical care need further improvement:

- Often, babies may have had their first glucose measurement too soon (44% of term babies were tested within the first hour). This may have occurred during the physiological fall in blood glucose after birth and may have led to unnecessary intervention.
- Some babies (9%) were given supplemental feed or glucose because of local routine practice only, possibly compromising the establishment of breastfeeding.
- Optimal blood glucose testing method was used in less than one-third of cases.
- One-third of term babies were admitted to a neonatal unit for special care. The results suggest that many (67%) admissions were possibly avoidable. Alternative strategies to routine neonatal unit admission for babies of mothers with diabetes could be postnatal wards with adequate clinical support, or transitional-care nurseries where the baby is nursed alongside mother.
- Fifty-three percent of women intended to breastfeed. This compares with an initial breastfeeding rate of 69% in the general population.

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10 | Key findings

10.1 The health of babies

Key finding 1

The babies of women with diabetes in the UK continue to have an increased risk of perinatal mortality and congenital malformations compared to the babies of mothers without diabetes.

This study is the largest nationwide study undertaken of pregnant women with diabetes in the UK and includes the largest coverage of women with pre-gestational type 2 diabetes. Nearly 15 years on from the St Vincent Declaration, babies born to women with diabetes in the UK continue to have high perinatal mortality rates, nearly four times greater than for those of women in the general population. The risk of congenital malformation in the babies of women with diabetes is nearly three times greater. Evidence for good periconceptional glycaemic control leading to improved perinatal outcome has been available since the 1980s and has been reinforced by randomised control evidence in 1996.¹ Despite this, pregnancy outcomes for women with diabetes in England, Wales and Northern Ireland remain poor. Similar rates have also been found in Scotland.²

10.2 Type 2 diabetes – different needs, equivalent risks

Key finding 2

Women with type 2 diabetes are more likely to:

- live in a deprived area
- come from a Black or Other ethnic minority.

The babies of women with type 2 diabetes have comparable risks of perinatal mortality and congenital malformation to those of babies of women with type 1 diabetes.

There is an increasing number of young women of childbearing age in the UK being diagnosed with type 2 diabetes. Half of the women with type 2 diabetes in this study came from an ethnic minority background and were more likely to live in a deprived area. Women with type 2 diabetes have different needs to women with type 1 diabetes and the majority will be required to change to insulin before or during pregnancy. Compared with women with type 1 diabetes, these women were less likely to have had a glycaemic control test prior to pregnancy, less likely to have received preconception counselling and less likely to have taken folic acid supplementation. Factors relating to the availability and accessibility of health services may be contributing to the observed suboptimal outcomes for people from ethnic minorities or disadvantaged groups. These issues need to be addressed, not only because

of adverse pregnancy outcomes but because these women are at an increased risk of other serious health complications not related to pregnancy in their lifetime.

This study is the first with sizeable numbers (over 200 women) describing pregnancy outcomes for women with pre-gestational type 2 diabetes. It finds that perinatal mortality for the babies of women with type 2 diabetes are comparable to those with type 1 diabetes. Type 2 diabetes has traditionally been considered as a less serious condition than type 1 diabetes.³ Health professionals and women of childbearing age need to be aware of these increased risks and be just as vigilant with preconception planning and care as for women with type 1 diabetes.

10.3 Prevalence of type 2 diabetes in pregnancy – regional variation

Key finding 3

The prevalence of type 2 diabetes in pregnancy varies considerably in England, Wales and Northern Ireland.

The areas in which the prevalence of type 2 diabetes in pregnancy is greatest do not necessarily coincide with those in which the prevalence of diabetes is greatest in the general population. Healthcare commissioners need to be aware of this when planning provision of services.

The prevalence of diabetes in pregnancy was one in 264 births in England, Wales and Northern Ireland. Type 2 diabetes accounts for 28% of pre-existing diabetes in pregnancy (one in 955 births) and varies from 13% in Wales to 45% in London. The regions in which the prevalence of type 2 diabetes in pregnancy is high do not necessarily coincide with the regions in which diabetes is most prevalent overall. The overall prevalence of diabetes is high where there is an ageing population such as the South West and coastal regions. Additional education, help and support for women with diabetes during childbearing years has resource implications. Healthcare commissioners in the regions of high prevalence of diabetes in pregnancy need to be aware of this.

10.4 Preconception care

Key finding 4

Women with diabetes are poorly prepared for pregnancy:

- only 39% took folic acid before conception
- only 35% had documented prepregnancy counselling
- only 37% were reported to have had a glycaemic control measurement before pregnancy.

Perhaps one of the most striking findings of this study is the apparently poor preparation of women with diabetes for pregnancy. This was demonstrated by the poor uptake of folic acid, the relatively small numbers of women who received prepregnancy counselling or had a documented glycaemic control test in the 6 months before pregnancy. Concerns regarding the effectiveness of the services delivering preconception care for these women were raised previously in the first CEMACH report on diabetes in pregnancy.⁴

The poor uptake of folic acid supplements parallels the position for pregnancy by women in general in the UK⁵ rather than being specific to women with diabetes. Not taking folic acid is linked to social deprivation. Some countries have introduced fortified food, notably flour with folic acid, to reduce neural tube defects rather than relying on health-seeking behaviour and supplementation periconceptionally.⁶ This approach may need to be debated by policy makers in the UK.

Babies of mothers with diabetes were at greater risk (3.1-fold) of neural tube defects than the general population (see Chapter 7). Although the minimum effective dose of folic acid needed to reduce this risk is not established, national guidelines recommend that women with diabetes should take a higher dose (5 mg) before conception up to the 12th week of pregnancy.^{7,8}

The majority of women in England, Wales and Northern Ireland in 2002/03 commenced pregnancy with suboptimal control of blood glucose. Education regarding the importance of preparation for pregnancy is a priority. Structured education packages are being introduced in the UK. Dose Adjustment for Normal Eating (DAFNE)⁹ is aimed at people with type 1 diabetes and a programme for 11–14 year olds is being piloted. Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND)¹⁰ is aimed at people with type 2 diabetes. It does not yet include pregnancy but, with the increasing numbers of young women of childbearing age being diagnosed with type 2 diabetes, this gap needs to be bridged.

The annual review conducted by the adult diabetes service is also an opportunity for ensuring women with diabetes of childbearing age are educated regarding the benefits of preparing for pregnancy. Primary and secondary care services should aim to develop joint protocols based on national guidelines to ensure that all women with diabetes receive consistent pre-conception care of a high standard.

10.5 Glycaemic control

Key finding 5

Only 38% of women with an HbA_{1c} value measured by 13 weeks of gestation had a value of less than 7%.

All mothers, regardless of type of diabetes or ethnic group, should be entering pregnancy with substantially better glycaemic control, while taking hypoglycaemic risk into account.

All mothers, regardless of type of diabetes, should be entering pregnancy with substantially better glycaemic control than that observed in this study. Seventy-two percent of women in this study had a documented HbA_{1c} test by 13 weeks of gestation. Of these women, 38% managed to achieve glycaemic levels within the recommended range of less than 7%. This does not compare well with other European countries, such as The Netherlands, where 75% of women with type 1 diabetes achieved HbA_{1c} of 7% or less by the first trimester.¹¹ It suggests that considerable improvements in periconceptional glycaemic control can be achieved in the UK population.

It is accepted that good glycaemic control reduces the risk of adverse perinatal outcomes. The evidence is better established for reducing congenital anomalies than for unexplained stillbirths. This study shows a higher average HbA_{1c} throughout pregnancy in mothers who went on to have normally formed stillbirth or neonatal death than in mothers who had a

good pregnancy outcome. This supports the importance of striving for good control during pregnancy.

Can the St Vincent Declaration be achieved? Good control does not necessarily equate with good outcome. Of mothers who had a HbA_{1c} of less than 7% by the first trimester, one-quarter of their babies had a congenital anomaly. The study from The Netherlands in which 75% of women with type 1 diabetes had a HbA_{1c} of 7% or less reported a high perinatal mortality rate, comparable to that observed in this study. The study in The Netherlands was, however, based on small numbers and the women reported a high proportion of hypoglycaemic episodes. HbA_{1c} value acts as a surrogate for 'control' but it does not measure fluctuations of glucose levels. Further research in this area is needed to identify other markers that may give better insight into how to reduce adverse perinatal outcomes.

10.6 High preterm delivery rate and caesarean section rate

Key finding 6

There is a 36% preterm delivery rate and 67% caesarean section rate for women with diabetes.

The experience of pregnancy and childbirth for women with diabetes is very different to that of the general maternity population. Women with diabetes are at greater risk of experiencing preterm (prior to 37 weeks of gestation) and caesarean delivery. Two-thirds of women underwent caesarean section and more than half of those were emergency procedures. Behind these high intervention rates is the conflict experienced by health professionals and women between continuing the pregnancy in order to achieve a normal delivery versus expediting delivery to avoid an unexpected stillbirth. In recent years, there has been a tendency in uncomplicated pregnancies to carry on to as near 40 weeks as possible and this is reflected in the consensus standard for the study on the timing of delivery. The decision for optimum timing for delivery rests with the woman and the health professionals providing her maternity care and should be based on the most accurate evidence of risks to her and the baby.

10.7 Large babies and difficult deliveries

Key finding 7

Over half of singleton babies' birth weights were over the 90th centile for birth weight.

Incidence of shoulder dystocia and Erb's palsy was increased.

Women with diabetes gave birth to larger babies than the general maternity population of England, Wales and Northern Ireland, with half of the babies being above the 90th centile for birth weight.

These large babies are subject to increasing risk of birth trauma. The risk of Erb's palsy was 4.5 per 1000 births, representing a ten-fold increase over that for babies delivered in the general maternity population. The risk of shoulder dystocia was 79 per 1000 vaginal births, a two-fold increase over that for babies delivered in the general maternity population.

10.8 Neonatal care

Key finding 8

One-third of term babies were admitted to a neonatal unit for special care.

Healthy babies of women with diabetes should not be routinely admitted to the neonatal unit. The results suggest that there should be alternative strategies to routine neonatal unit admission of babies of mothers with diabetes.

There was frequent failure to use reliable glucose tests in babies.

Intention to breastfeed was lower among mothers with diabetes than the breastfeeding rate in the general population.

One-third of term babies were admitted to a neonatal unit for special care and separated at birth from their mothers for an average of 3 days. This compares with less than 10% for term births in the UK.¹² Two-thirds of these separations were considered potentially avoidable. Care could have been delivered in an alternative environment such as a postnatal ward with adequate clinical support or a transitional-care nursery, which would avoid separation of the mother and the baby. Local services need to review the type of care provided.

Babies should have a test of blood glucose concentration by 4–6 hours of age before a feed. Although most (83%) babies had a glucose measurement within 6 hours, the method used was not always reliable. Despite glucose reagent strips being contraindicated for use in neonates, they were used in 35% of cases.

Breast milk is the food of choice for babies of mothers with diabetes. Fifty-three percent of women with diabetes intended to breastfeed. This compares with an initial breastfeeding rate of 69% in the general population. Local services should support practices and education that encourage women to consider breastfeeding, as for all groups of babies, especially those vulnerable to neonatal complications or risk of diabetes in later life.

10.9 What do these findings mean for the future?

The high perinatal mortality rate in the UK parallels findings from other European countries, which range from 27.8 to 48 per 1000 births.^{2,11,13–15} There has been little success, universally, in achieving the St Vincent Declaration and translating evidence into practice. More work is required to elucidate how women with diabetes, regardless of type, can be best enabled to improve the outcomes of their pregnancy. This applies in particular to preconception preparation. The best outcomes will be achieved if there is an effective partnership between the women and the health professionals responsible for her. The challenge for the health professional is how best to empower women with diabetes to fully participate in this partnership.

There are increasing numbers of young women in the UK being diagnosed with type 2 diabetes. In addition to this, the prevalence of type 1 diabetes in children under five is also increasing, so the issues identified in 2002/03 are likely to become more problematic in the next two decades unless concerted action is taken now. The delivery strategy for the National Service Framework for Diabetes was released in 2003 and the findings from this study will act as a reference for future progress in addressing this public health concern.⁷

Enhanced preconception services and future research on understanding the biological and sociological reasons as to why these women have adverse pregnancy outcomes are a priority.

This study has demonstrated a clear need to develop and implement effective strategies for the education, wellbeing and health care of women with diabetes of childbearing age.

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Appendix A
Diabetes CESDI notification form and standards
dataset form

Surname:
 First Name:
 Date of Birth:
 Hospital Number:
 Postcode:

Attach hospital label if possible

Reference Number:

Please fill in at same time as pregnancy details

Diabetes CESDI PREGNANCY DETAILS

Reference Number:

In what year was this woman's diabetes diagnosed? (year)

Hospital of booking:(hospital name)

Expected hospital of delivery:(hospital name/as above)

Last menstrual period (LMP): (dd/mm/yy) not known

Expected date of delivery (EDD) by LMP: (dd/mm/yy) not known

EDD by early ultrasound scan (USS): (dd/mm/yy) not known

Your name: Contact Tel:

Diabetes CESDI DELIVERY DETAILS

Reference Number:

Actual hospital of delivery:(hospital name)

Gestation at delivery: weeks days not known

Date of delivery: (dd/mm/yy) Time of delivery: (24hr clock)

Birth Order: Singleton Twin 1 Twin 2 If triplets or more, write birth order in box

Baby's hospital no:

Baby's NHS no:

Your name: Contact Tel:

Diabetes CESDI OUTCOME DETAILS

Reference Number:

Alive at 28 days; If not please complete both sections below as appropriate

SECTION 1

Loss before 20 completed weeks'

Late fetal loss (20+0 - 23+6 weeks')

Stillbirth

Neonatal death

Date of death: (dd/mm/yy)

SECTION 2

Legal Abortion

Congenital malformation diagnosed:

Antenatally

At delivery

Neonatally

None diagnosed

Description of malformation.....

Your name: Contact Tel:

Date of completion:

- Answer all questions unless otherwise specified
- If this is an additional baby in a multiple birth, only answer questions 15, 20, 21, 23 and 24 – 34
- If indicated in the righthand column, please read the definition on the back of the separator page BEFORE completing the question
- The standard of care to which the question relates is in the righthand column; standards are printed on the back of this notification pack

ANSWER QUESTIONS 1 – 15 FOR ALL BABIES

SECTION I. BACKGROUND INFORMATION

1 What is this woman’s ethnic origin?

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> White | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Black African | <input type="checkbox"/> Bangladeshi |
| <input type="checkbox"/> Black Caribbean | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Black other | <input type="checkbox"/> Other |
| <input type="checkbox"/> Indian | |

Describe:.....

2 Past obstetric history: TICK ONE OPTION ONLY

- No previous pregnancy
- At least one previous pregnancy. *If you have ticked this option, please complete table below*

Year	Gestation at delivery	Mode of delivery	Description of outcome <i>(miscarriage, termination of pregnancy, stillbirth, neonatal death, postneonatal death, alive)</i>

Total number of pregnancies

3 What type of pre-existing diabetes does this woman have?

- Type 1 diabetes
- Type 2 diabetes
- Other

Specify:.....

See
Definitions

4 In what year was the diabetes diagnosed?

Do NOT include any woman with gestational diabetes

..... year

5 Was this woman on insulin before her last menstrual period?

- Yes
- No
- Don't know

Standard 5

SECTION II. PRE-PREGNANCY CARE

6 Was this woman taking folic acid before her last menstrual period?

- Yes
- No
- Don't know

Standard 2

7 Do you know the most recent pre-pregnancy HbA_{1c} value (or local equivalent test) within 6 months prior to conception? **TICK ONE OPTION ONLY**

- No
- Yes (If you have ticked this option, please complete table below)

See
Definitions
Standard 5

Date of test <i>dd/mm/yy</i>	Type of test	Result	Laboratory range for good control

8 Is there any evidence that this woman had pre-pregnancy counselling?

- Yes
- No

Standard 1

9 By what means did this woman receive pre-pregnancy counselling?

Standard 1

Please describe (e.g. at diabetes clinic, formal pre-pregnancy clinic, GP etc)

OR Not applicable

SECTION III. PREGNANCY CARE BEFORE 23 WEEKS' GESTATION

10 Was a detailed retinal assessment carried out during this pregnancy?

See
Definitions
Standard 4

- Yes
- No
- Don't know

11 Was the woman provided with a glucagon kit in this pregnancy?

Standard 3

- Yes
- Woman already had glucagon kit before pregnancy
- No
- Reason:.....*
- Don't know

12 Please enter the two HbA_{1c} tests (or local equivalent tests) which correspond most closely, either before or after, to the gestations stated below:

See
Definitions
Standard 5

Gestation (weeks)	Test not performed	Date of test	Type of test	Gestation test performed (wks + days)	Result	Laboratory range for good control
10						
20						

13 Did this woman have a dating ultrasound scan?

Standard 6

- Yes
Gestation performedwksdays
- No
- Reason:.....*
- Don't know

14 Was a detailed anomaly scan performed after 16 weeks' gestation?

Standard 6

- Yes
Gestation at which first performedwksdays
- No
Reason:.....
- Don't know
- Not applicable (pregnancy loss before 16 weeks')

15 Was the anomaly scan:

Standard 6

- Normal
- Not normal (*fetal anomalies only*)
Describe findings:.....
- Result not known
- Anomaly scan not performed

STOP HERE IF THIS IS A DELIVERY BEFORE 23+0 WEEKS' GESTATION

**SECTION IV.
PREGNANCY CARE AFTER 23+0 WEEKS' GESTATION**

16 How many ultrasound scans were performed for the purpose of assessing fetal growth after 23 weeks' gestation?

Standard 6

Number of scans :

- Don't know

17 Please enter the HbA_{1c} test (or local equivalent test) which corresponds most closely, either before or after, to the gestation stated below:

See
Definitions
Standard 5

Gestation (weeks)	Test not performed	Date of test	Type of test	Gestation test performed (wks + days)	Result	Laboratory range for good control
34						

18 Was a full course of antenatal steroid therapy given, if the woman delivered before 36 weeks' gestation?

See
Definitions
Standard
12

- Woman delivered after 36 weeks' gestation
- Yes
- No opportunity
- No
Reason:.....
- Don't know

SECTION V. CARE DURING LABOUR AND DELIVERY

19 Onset of labour:

- Spontaneous
- Induced following ruptured membranes
- Induced for any other reason
Indication:.....
- Not in labour
- Don't know

See
Definitions
Standard 8

20 The mode of delivery was:

- Spontaneous vaginal delivery
- Ventouse
- Forceps
- Assisted breech delivery
- Emergency caesarean section
Indication:.....
- Elective caesarean section
Indication:.....

See
Definitions
Standard 8

21 Was continuous electronic fetal monitoring used in labour?

- Yes
- No
- Offered but declined by woman
- Not in labour
- Don't know
- Not applicable (*intrauterine fetal death before labour*)

Standard 9

22 Was the woman receiving an intravenous infusion of insulin and dextrose at the time of delivery?

- Yes
- No
- No time to administer
- Don't know

Standard
10

23 If this was a vaginal delivery was shoulder dystocia documented?

- Not a vaginal delivery
- Yes
- No
- Don't know

See
Definitions
Standard
11

SECTION VI. NEONATAL CARE

24 What is the sex of the baby?

- Male
- Female

25 What was the birth weight of the baby?

.....grams

26 Is there any documented evidence of fetal trauma?

- Erb's palsy
- Fracture
Specify:.....
- Other
Describe:.....
- No

Standard
11

COMPLETE QUESTIONS 27 – 34 FOR LIVEBIRTHS ONLY

27 What was the Apgar score at 5 minutes of age?

28 At what age did the baby have its first blood glucose test?

.....hoursminutes

- Don't know
- Not applicable

Standard
17

29 What methods were used to test the baby's blood glucose in the first 24 hours after delivery? TICK MORE THAN ONE OPTION IF NECESSARY

- Reagent strip testing
- Laboratory-based method
- Haemacue
- Glucose electrode (e.g. blood gas machine, YSI electrode)
Specify type:.....
- Don't know
- Not applicable

Standard
18

30 What was the age of the baby at first oral feed in the first 24 hours after delivery?

Standard 15

.....hoursminutes

- No oral feeds in the first 24 hours
- Don't know
- Not applicable (*early neonatal death*)

31 Was the baby separated from its mother to receive any of the following types of care after delivery?

See Definitions Standard 14

- No
- Yes, special care
- Yes, high dependency intensive care (level 2 intensive care)
- Yes, maximal intensive care (level 1 intensive care)
- Yes, other
please specify:.....
- Not applicable (*early neonatal death*)
- Don't know

Documented reason for needing this care:

For how long did the baby receive this care?:day(s)

Documented diagnoses on discharge from this care:

32 Was supplemental milk or glucose in the first 24 hours after delivery given as: TICK ONE OPTION ONLY

Standard 19

- Not given
- Not applicable (*early neonatal death*)
- A response to a low blood glucose level only
specify lowest known value..... (mmol/l)
- A response to clinical signs of hypoglycaemia only
- A response to a low blood glucose level AND clinical signs of hypoglycaemia
- Routine practice
- Other
specify:.....

33 What was the mother's chosen method of feeding at delivery? (*this refers to the mother's preferred method even if it could not be implemented in practice*)

**Standard
16**

- Breastfeeding
- Formula milk
- Breast feeding AND formula milk
- Don't know

34 Please tick the statement which is most applicable to the feeding method at 28 days:

**Standard
16**

- Breast milk only
- Breast milk and formula
- Formula milk only
- Other
- Describe:.....
- Don't know
- Not applicable (*neonatal death*)

Appendix B

Congenital malformation groupings with ICD10 codes

Groups	ICD10–BPA^a
Nervous system	Q00.0–Q07.9
Neural tube defects	Q00.0–Q01.9, Q05.0–Q05.9
Remainder of central nervous system	Q02.0–Q04.9, Q06.0–Q07.9
Eye	Q10.0–Q15.9 [excluding Q10.5, see ICD10 Appendix B]
Ear	Q16.0–Q16.9
Congenital heart disease	Q20.0–Q26.9 [excluding Q25.0, see ICD10 Appendix B]
Cleft lip (with or without palate)	Q36.0–Q37.9
Cleft palate	Q35.0–Q35.9
Digestive system	Q39.0–Q45.9
Internal urogenital system	Q51.5, Q51.6, Q52.0–Q52.9, Q54.0–Q56.9, Q64.0 [excluding Q54.0, Q54.4, see ICD10 Appendix B]
External genital system	Q51.5, Q51.6, Q52.0–Q52.9, Q54.0–Q56.9, Q64.0 [excluding Q54.0, Q54.4, see ICD10 Appendix B]
Limb, musculoskeletal and connective tissue	Q18.0–Q18.8, Q30.0–Q30.8, Q38.0, Q38.2–Q38.9, Q65.0–Q65.6, Q66.0–Q66.9, Q67.0–Q68.0, Q68.2–Q68.5, Q68.8, Q69.0–Q79.9, Q87.0, K0.70, K07.9 [excluding Q66.2, Q66.4, Q66.8, Q67.7, Q76.0, Q76.7 see ICD10 Appendix B]
Chromosomal	Q90.0–Q94, Q96–Q99
Trisomy 21	Q90.0
Other chromosomal	Q91.0–Q94, Q96–Q99

^aInternational Classification of Diseases, Revision 10 (ICD10) with British Paediatric Association extension

Appendix C

Minor anomalies to be excluded unless part of a syndrome complex

Group	ICD10
Eye	
Stenosis or stricture of lacrimal duct	Q10.5
Ear	
Minor or unspecified anomaly of ear	Q17.9
Pre-auricular appendage, tag or lobule	Part of Q17.0
Other appendage, tag or lobule	Part of Q17.0
Congenital heart disease	
Patent ductus arteriosus in babies <37 weeks of age or <2500 g in weight	Q25.0
Respiratory system	
Minor or unspecified anomaly of nose	Q30.9
Digestive system	
Hiatus hernia	Q40.1
Internal urogenital system	
unspecified renal agenesis/hypoplasia	Q60.2, Q60.5
External urogenital system	
Undescended testicle and unspecified ectopic testicle	Q53.0–Q53.9
Chordee	Q54.4
Glandular hypospadias	Q54.0
Limb	
Postural or unspecified metatarsus varus or metatarsus adductus	Q66.2
Postural or unspecified talipes calcaneovalgus or pes calcaneovalgus	Q66.4
Clubfoot of postural origin	Q66.8
Musculoskeletal system and connective tissue	
Unspecified malformations of the head and neck	Q18.9
Unspecified malformations of the nose	Q30.9
Tongue tie	Q38.1
Pectus excavatum	Q67.6
Spina bifida occulta uncomplicated	Q76.0
Malformation of the sternum	Q76.7
Other nonchromosomal	
Naevus, birth mark	Q82.5
Abnormal palmar crease	Q82.80
Skin tag	Q82.81
Accessory or ectopic nipple	Q83.3
Minor anomaly of nipple	Part of Q83.8

Appendix D

Standards of care

A preconception clinic should be run jointly by the adult diabetes service and the maternity service for women wishing to become pregnant.

[Diabetes NSF – illustrative service models; www.publications.doh.gov.uk/nsf/diabetes/ch2/service/models/pregnancy.htm]

Women with diabetes have an increased risk of neural tube defects and should be offered prepregnancy folic acid supplements, continuing up to 12 weeks of gestation.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

All women with diabetes should be referred promptly for a first-trimester ultrasound scan to enable accurate dating of the pregnancy.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

If delivery is indicated before 34 weeks, administration of corticosteroids should be considered to prevent neonatal respiratory distress syndrome.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Women should be encouraged and supported to monitor their blood glucose levels regularly and to adjust their insulin dosage, in order to maintain their blood glucose levels within the normal (non-diabetic) range. The aim should be for the woman to maintain her HbA_{1c} below 7.0%.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Hypoglycaemia should be discussed and glucagon made available with clear instructions on its use.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

A full retinal assessment should be undertaken in all women with pre-existing diabetes during the first trimester or at booking if this is later.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Labour and delivery should be undertaken in a maternity unit with facilities for the resuscitation and stabilisation of babies and with personnel skilled in advanced resuscitation immediately available on a 24-hour basis.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

The mode and timing of delivery should be determined on an individual basis, aiming to realise a spontaneous vaginal delivery by no later than 40 weeks of gestation, if possible.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Continuous electronic fetal heart monitoring should be offered to all women with diabetes during labour and fetal blood sampling should be available if indicated.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Intravenous dextrose and insulin should be administered during labour and delivery following an agreed multidisciplinary protocol.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

All babies should remain with their mothers during the neonatal period unless there is a specific medical indication for admission to a neonatal intensive care unit.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Babies born to women with diabetes should be fed as soon as possible after birth and all should receive their first feed within 4 hours of birth, unless contraindicated for medical reasons.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

Breastfeeding is recommended but all mothers should be supported in the feeding method of their choice.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Babies of mothers with diabetes should have a test of blood glucose concentration by 4–6 hours of age, before a feed.

[Diabetes NSF – Intervention details; www.publications.doh.gov.uk/nsf/diabetes/ch2/interventions/pregnancy.htm]

The diagnosis of hypoglycaemia should be made using a ward-based glucose electrode or laboratory method and not by reagent strip testing.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Interventions for the management of hypoglycaemia should be guided by blood glucose level and clinical assessment.

[CEMACH Diabetes Multidisciplinary Resource Group – standard derived from SIGN Guideline No. 9]

Appendix E

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Confidential Enquiry into Maternal and Child Health

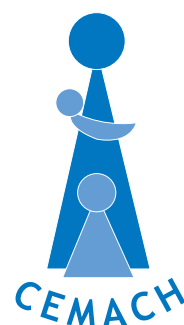
Improving the health of mothers, babies and children

PREGNANCY IN WOMEN WITH TYPE 1 AND TYPE 2 DIABETES

2002–2003

England, Wales and Northern Ireland

Executive Summary



Executive Summary

Women with diabetes are at an increased risk of losing a baby during pregnancy and of having a baby with a congenital anomaly. Good periconceptional glycaemic control reduces the risk of these adverse perinatal outcomes. The St. Vincent Declaration (1989) set a clear target of achieving pregnancy outcomes in women with diabetes equivalent to those of the general maternity population within five years.

The CEMACH diabetes programme

The Confidential Enquiry into Maternal and Child Health (CEMACH) diabetes programme was set up to evaluate pregnancy outcomes and the quality of maternity care for women with diabetes in England, Wales and Northern Ireland. It is the largest study of diabetes in pregnancy ever conducted and includes information on 3808 pregnancies of women with diabetes who delivered or booked in 231 hospitals in England, Wales and Northern Ireland between 1 March 2002 and 28 February 2003. Data were collected on standards of care for these women and their babies from preconception to the postnatal period. This forms the basis of the report *Pregnancy in Women with Type 1 and Type 2 Diabetes in 2002–2003, England, Wales and Northern Ireland*.

Key finding 1: Perinatal outcomes remain poor

The babies of women with diabetes continue to have an increased risk of perinatal mortality (3.8-fold) compared with the babies of mothers in England, Wales and Northern Ireland (Table 1).

Table 1: Maternal age-adjusted stillbirth, perinatal and neonatal mortality in babies born to women with type 1 and type 2 diabetes in England, Wales and Northern Ireland, 01/03/02–28/02/03

	Women with diabetes (type 1 and 2)		National rate (<i>n</i> = 620 841) ^c	Rate ratio [95% CI]
	Frequency	[95% CI]		
Stillbirth ^a	63	26.8 [19.8–33.8]	5.7	4.7 [3.7–6.0]
Perinatal death ^a	75	31.8 [24.2–39.4]	8.5	3.8 [3.0–4.7]
Neonatal death ^a	22	9.3 [5.2–13.3]	3.6	2.6 [1.7–3.9]

^a Rate per 1000 live births + stillbirths.
^b Rate per 1000 live births.
^c Source for national data: CEMACH 2005.

The prevalence of confirmed major anomalies was 41.8 per 1000 births compared with 21 per 1000 births for babies of mothers in general, as reported to the European Surveillance of Congenital Anomalies (EUROCAT). This increase is primarily due to a higher number of neural tube defects (3.4-fold) and congenital heart disease (3.3-fold).

Key finding 2: Type 2 diabetes – different needs, equivalent risks

There are an increasing number of women of childbearing age in the UK being diagnosed with type 2 diabetes. They have different needs to women with type 1 diabetes and the majority will need to commence insulin during or before pregnancy. This study describes outcomes for 1401 women with pre-gestational type 2 diabetes. It found that the perinatal mortality rate for babies of women with type 2 diabetes, born between 1 March 2002 and 28 February 2003, was as high as that for babies of women with type 1 diabetes (Table 2).

Table 2: Stillbirth, perinatal and neonatal mortality in babies born to women with type 1 and type 2 diabetes in England, Wales and Northern Ireland, 01/03/02-28/02/03

	Type 1		Type 2	
	Frequency	Rate [95% CI]	Frequency	Rate [95% CI]
Stillbirth ^a	44	25.8 [18.3–33.3]	19	29.2 [16.3–42.2]
Perinatal death ^a	54	31.7 [23.3–40.0]	21	32.3 [18.7–45.9]
Neonatal death ^b	16	9.6 [4.9–14.3]	6	9.5 [1.9–17.1]

^a Rate per 1000 live births + stillbirths.
^b Rate per 1000 live births.
^c Source for national data: CEMACH 2005.

Women with type 2 diabetes compared with women with type 1 diabetes were less likely to have had a glycaemic control test prior to pregnancy (29% compared with 40%), pre-pregnancy counselling (25% compared with 38%) or uptake of folic acid supplementation (29% compared with 43%). Given the high risks of adverse perinatal outcome, type 2 diabetes should not be viewed as a less serious condition in pregnancy than type 1 diabetes. Health professionals and women with type 2 diabetes need to be aware of this and to be just as vigilant with pre-pregnancy planning and care as is the case for type 1 diabetes.

Half of the women with type 2 diabetes come from a Black, Asian or Other ethnic minority and just under half (45%) live in a deprived area. Factors relating to the availability and accessibility of health services for people from ethnic minorities or disadvantaged social groups may be contributing to these observed suboptimal outcomes. These issues need to be addressed.

Key finding 3: Prevalence of type 2 diabetes in pregnancy

Pre-gestational type 2 diabetes in pregnancy occurred in one in every 955 births and accounted for 27.6% of diabetes in pregnancy. The reported proportion of type 2 diabetes ranged from 13.3% in Wales to 44.5% in London (Figure 1).

The regions with high prevalence of type 2 in pregnancy did not necessarily coincide with regions where the overall prevalence of diabetes in the general population is high. Health commissioners need to be aware of the variation in prevalence of type 2 diabetes in pregnancy when planning provision of services.

Key finding 4: Poor preparation for pregnancy

Women with diabetes, irrespective of type of diabetes, are poorly prepared for pregnancy. There was documented evidence of:

- 35% receiving preconception counselling
- 37% having a preconception glycaemic control measurement
- 39% taking folic acid supplements before conception.

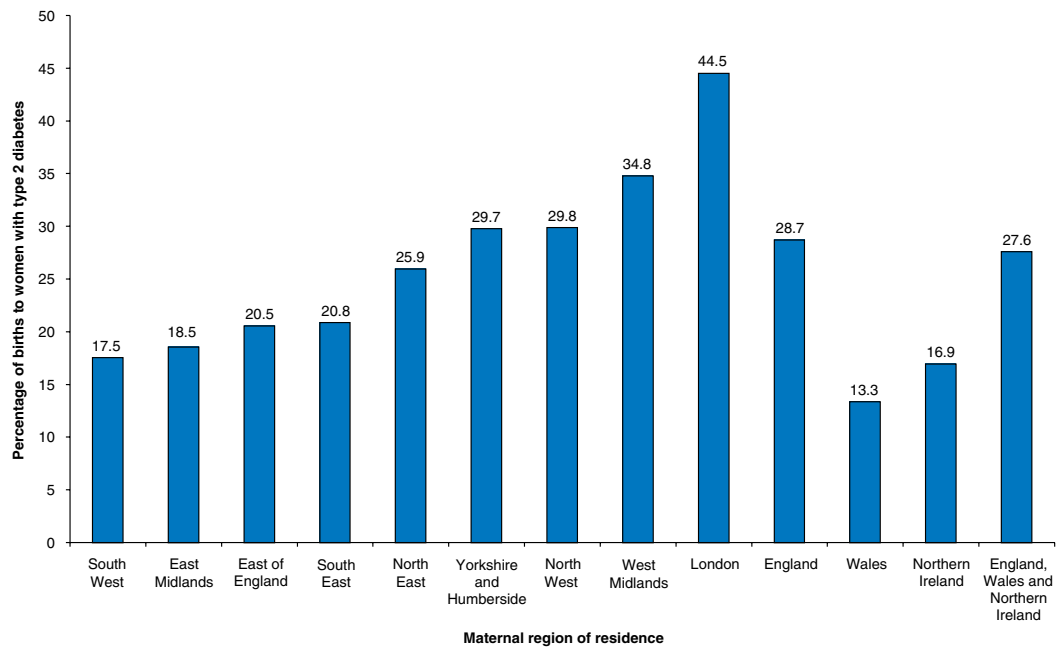


Figure 1: Proportion of births to women with type 2 diabetes by maternal region of residence

The low level of documented uptake of folic acid supplements parallels the position for pregnancy in general in the UK rather than being specific to women with diabetes. However, an additional concern for the babies of mothers with diabetes is the increased risk (3.4-fold) of neural tube defect compared with that of babies of mothers in general. Women with diabetes should take the higher dose of folic acid (5 mg) from before conception up to the 12th week of pregnancy, as recommended by the National Service Framework (NSF) for Diabetes.

Key finding 5: Glycaemic control – poor pre-pregnancy levels

Other studies have shown that good glycaemic control reduces the risk of adverse perinatal outcomes. Mothers who had a poor pregnancy outcome (stillbirth, congenital anomaly, neonatal death) had higher HbA_{1c} levels before pregnancy and at all stages throughout pregnancy than mothers who had a healthy baby (Figure 2).

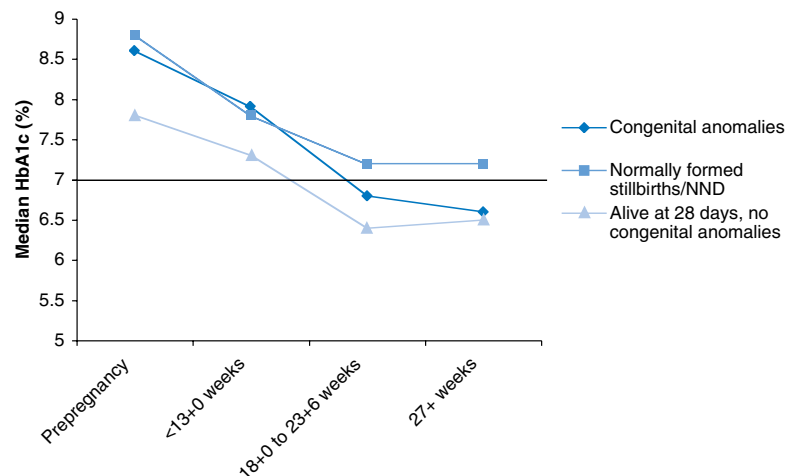


Figure 2: Median HbA_{1c} test results at various stages of pregnancy according to perinatal outcome

HbA_{1c} should be used to monitor long-term glycaemic control and the NSF for Diabetes recommends that glycaemic levels of HbA_{1c} should be less than 7% at the time of conception. Only 38% of women with an HbA_{1c} test by 13 weeks of gestation managed to achieve

glycaemic levels within the recommended range (less than 7%). Efforts need to be made to ensure that all groups of mothers, regardless of type of diabetes or ethnic group, enter pregnancy with substantially better glycaemic control, while taking hypoglycaemic risk into account.

Key finding 6: High preterm delivery rate and caesarean section rate

The experience of pregnancy and childbirth for a woman with diabetes is very different to that for a woman in general. A woman with diabetes is much more likely to be delivered early, require an induction of labour or to be delivered by caesarean section (Table 3).

Table 3: Preterm deliveries, induction and caesarean section in 2002–03

	Women with diabetes (%)	Women in England and Wales (%) ^a
Deliveries before 37 weeks	36	7
Induction of labour	39	21
Caesarean section	67	22
Emergency caesarean section	38	13
^a HES data		

Behind these high intervention rates is the tension between continuing the pregnancy in order to achieve a normal delivery versus expediting delivery to avoid an unexpected stillbirth. The decision for optimum timing for delivery should be based on the most accurate evidence of risks to the mother and her baby.

Key finding 7: Large babies and difficult deliveries

The babies of women with diabetes are bigger and are at increased risk of a difficult delivery. For singleton babies of mothers with diabetes, 21% weighed above 4 kg, 6% weighed above 4.5 kg. The corresponding figures for singleton babies of mothers in England and Wales are 11% above 4 kg and 2% above 4.5 kg. There was a higher risk of shoulder dystocia (79/1000 vaginal births) and Erb's palsy (4.5/1000 births) in these babies compared with that for babies of mothers in general.

Key finding 8: High separation rates from mother at birth, failures to use reliable glucose test in baby and low breastfeeding rates

Ideally, the baby should remain with the mother and should only be admitted to a neonatal unit for a specific medical indication. One-third of term babies (33%) were admitted to a neonatal unit. Two-thirds of these admissions were potentially avoidable. From examination of the reasons given, 26% were described as 'routine' and 42% were for minor clinical conditions. Units need to consider transitional care arrangements or ways to improve safe monitoring on the normal postnatal wards for these babies.

Babies should have a test of blood glucose concentration by 4–6 hours of age before a feed. Although most (83%) babies had a glucose measurement within 6 hours, the method used was not always reliable. Despite glucose reagent strips being contraindicated for use in neonates, they were used in 35% of cases.

Breast milk is the food of choice for babies of mothers with diabetes. Fifty-three percent of women with diabetes intended to breastfeed. This compares with an initial breastfeeding rate of 69% in the general population. Local services should support practices and education that encourage women to consider breastfeeding.

Conclusion: What do these findings mean for the future?

Both women with type 1 and those with type 2 diabetes represent high-risk groups during pregnancy. As the incidence of diagnosed diabetes continues to increase, especially at young ages, the number of women with diabetes in pregnancy will also continue to increase. This study finds a nearly four-fold increase in perinatal mortality rate and two-fold increase in congenital anomaly rate in women with diabetes compared with that seen in the general maternity population. Despite evidence since the late 1980s that good glycaemic control around the time of conception and in early pregnancy can reduce these adverse outcomes, there appears to have been minimal improvement. The issues identified in 2002/03 are likely to become more problematic in the next two decades unless concerted action is taken now.

This study is substantially larger than any other in describing pregnancy outcomes for women with pre-gestational type 2 diabetes. It finds that the perinatal mortality rate for the babies of mothers with type 2 diabetes is as high as that for the babies of mothers with type 1 diabetes. It also finds that preparation for pregnancy in this group appears to be particularly poor. Health professionals and women of childbearing age with type 2 diabetes need to be aware of this and be just as vigilant with preconception planning and care as for women with type 1 diabetes.

More work is required to elucidate how women with diabetes regardless of type can be best enabled to improve the outcomes of their pregnancy. This applies in particular to preconception preparation. The best outcomes will be achieved if there is an effective partnership between the woman and the health professionals responsible for her. The challenge for health professionals is how to best empower women with diabetes to fully participate in this partnership.

This study has demonstrated a clear need to develop and implement effective strategies for the education, wellbeing and health care of women with diabetes of childbearing age. Enhanced preconception services and future research on understanding the reasons for these women having adverse pregnancy outcomes are a priority.

Acknowledgements

CEMACH thanks the many clinicians and staff in the 231 hospitals throughout England, Wales and Northern Ireland who provided data for this study. Without their continued support and commitment we would not have been able to produce this report.

A more detailed explanation of the study findings and supporting evidence can be found in the full report, which can be obtained from:

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Price £10
Please make cheques payable to CEMACH

The report can also be found on the CEMACH website: www.cemach.org.uk