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# Multidisciplinary care for pregnant women with cardiac disease: A mixed methods evaluation



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#### ABSTRACT

Background: Cardiac disease is associated with adverse outcomes in pregnancy and is the leading cause of indirect maternal death in the United Kingdom (UK) and internationally. National and international guidelines recommend women should receive care from multidisciplinary teams; however evidence is lacking to inform how they should be operationalised.

*Objectives*: To describe the composition and processes of multidisciplinary care between maternity and cardiac services before, during and after pregnancy for women with cardiac disease, and explore clinicians' (cardiologists, obstetricians, nurses, midwives) and women's experiences of delivering/receiving care within these models.

Design: Mixed-methods comprising case-note audit, interviews and observation.

Setting: Two inner-city National Health Service (NHS) maternity units in the south of England serving similar obstetric populations, selected to represent different models of multidisciplinary team care.

*Participants*: Women with significant cardiac disease (either arrhythmic or structural, e.g. tetralogy of fallot) who gave birth between June 1 st 2014 and 31 st May 2015 (audit/interviews), or attended an multidisciplinary team clinic (obstetric/cardiac) during April 2016 (observation).

*Methods*: A two-phase sequential explanatory design was undertaken. A retrospective case-note audit of maternity and medical records (n=42 women) followed by interviews with a sub-sample (n=7 women). Interviews were conducted with clinicians (n=7) and observation of a multidisciplinary team clinic in one site (n=8 women, n=4 clinicians).

Results: The interests and expertise of individual clinicians employed by the hospital trusts influenced the degree of integration between cardiac and maternity care. Integration between cardiac and maternity services varied from an ad-hoc 'collaborative' model at Site B to an 'interdisciplinary' approach at Site A. In both sites there was limited documented evidence of individualised postnatal care plans in line with national guidance. Unlike pathways for risk assessment, referral and joined care in pregnancy for women with congenital cardiac disease, pathways for women with acquired conditions lacked clarity. Midwives at both sites were often responsible for performing the initial maternal cardiac risk assessment despite minimal training in this. Clinicians and women's perceptions of 'normality' in pregnancy/birth, and its relationship to 'safe' maternity care were at odds.

Conclusion: The limited evidence and guidance to support multidisciplinary team working for pregnancy in women with cardiac disease – particularly those with acquired conditions – has resulted in variable models and pathways of care. Evidence-based guidance regarding the operationalisation of integrated care between maternity and cardiac services – including pathways between local and specialist centres – for all women with cardiac disease in pregnancy is urgently required.

#### What is already known about the topic?

- Cardiac disease particularly acquired conditions is the leading cause of indirect maternal death in the UK during or up to six weeks
- after pregnancy with no significant change in maternal mortality rates from cardiac disease between 2006 and 2015.
- Reports have called for access to a coordinated multidisciplinary team to improve outcomes for mother and infant, yet there is limited

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- evidence in health care literature, including systematic reviews, to support definition of optimal models of care.
- A survey of UK maternity providers has highlighted the lack of guidance for operationalising multidisciplinary teams, resulting in disparate models of care.

#### What this paper adds

- This is the first study of integrated care for women in pregnancy with pre-existing cardiac disease.
- Key findings include the lack of clear guidance/pathways for women
  with acquired conditions; the influence of individual clinicians' expertise and interest in pregnancy and cardiac conditions on the
  model of care provided; inadequate provision of training to ensure
  appropriate knowledge and skills for risk assessment and management; and lack of individualised care pathways for women.
- Research to identify the key elements of effective multidisciplinary team care across maternity settings and before, during and after pregnancy is needed.

#### 1. Introduction and background

Pre-existing cardiac disease (disease that exists prior to pregnancy, rather than pregnancy induced) affects between 0.2-4% of pregnant women in the United Kingdom (UK) (Simpson, 2012) and remains the leading indirect cause of maternal death globally (Australian Institute of Health and Welfare (AIHW) et al., 2014; Creanga et al., 2015; 2014; Haththotuwa et al., 2009; Engin-Ustun et al., 2012; Mocumbi et al., 2016), including in the UK and Ireland (Knight et al., 2016, 2017; Emmanuel and Thorne, 2015). This includes for example arrhythmias (acquired) and structural defects such as tetralogy of fallot (congenital). Approximately two thirds of cases seen in specialist clinics are congenital in nature (Ross-Hesselink et al., 2013) but this is likely to underestimate the prevalence of acquired conditions that often go undetected/un-referred to such clinics. Recent UK data published on severe morbidity and deaths from cardiac causes during 2009 to 2014 found lack of co-location of obstetric and cardiac services jeopardised interdisciplinary working, communication and referral between clinical specialties (Knight et al., 2016).

Guidelines published in a number of countries worldwide (including UK, Australia, Canada, Japan and South Africa) for the management of pregnant and postnatal women with cardiac disease have recommended that women should have access to a coordinated multidisciplinary team with input from specialist obstetric and medical professionals (Knight et al., 2016, 2017; Royal College of Obstetrics and Gynaecologists (RCOG), 2011; Sliwa et al., 2015; South Australia Maternal and Neonatal Clinical Network, 2014; Howlett et al., 2010; JCS, 2012). The multidisciplinary team members generally referred to in such guidelines include an obstetrician, cardiologist (or obstetric physician) and anaesthetist. Only one guideline (from Japan) (JCS, 2012) includes a nurse or midwife being present. This omission is despite some maternity care settings, such as in the UK, where all pregnant women have access to midwifery care as part of a universal health system, regardless of whether their pregnancies are deemed high or low risk (Department of Health (DH), 2010). In 2016 National Health Service England published 'Congenital Heart Disease Standards & Specifications'(NHS England, 2016) which included that women should have access to a multidisciplinary cardiac-obstetric team, and specifying referral pathways based on cardiac risk (based on the modified World Health Organization (WHO) criteria I-IV depending on risk of maternal mortality or morbidity; repaired tetralogy of fallot and unrepaired cyanotic heart disease are examples of WHO II and III respectively) (Regitz-Zagrosek et al., 2011). Team composition for specialist adult congenital heart disease centres should include "consultant obstetrician, midwives, adult congenital heart disease cardiologist, a nurse specialist and access to consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease. There is no equivalent guidance for women with acquired cardiac conditions. A UK-wide survey of current models of multidisciplinary team care for women with cardiac disease reported wide variability across the UK (Taylor et al., 2017) and a systematic review undertaken by the same team, identified limited primary evidence to inform the structure or working practices of such teams, their impact on clinical outcomes or patient experience (Bick et al., 2014).

Multidisciplinary team working, including the features of team composition, function and processes are well defined in national guidance in other clinical areas, including cancer care (National Institute for Health and Clinical Excellence (NICE), 2002) with evidence of benefits including improved patient outcomes (Taylor et al., 2013) and better coordinated patient care (Taylor and R. Multidisciplinary team members' views about MDT working, 2009). Team composition for breast cancer, for example, should include personnel who "have experience with breast cancer patients, substantial fixed time commitment to breast cancer patients, and where appropriate specialist qualifications in breast cancer work" Membership includes: breast surgeon (s), breast care nurse(s), pathologist, radiologist, oncologist, coordinator and team secretary.

Given that women with cardiac disease who become pregnant have (at least) two 'conditions', the guidance regarding management of co- or multi- morbidity is relevant to consider. In 2014, the Department of Health in England (Department of Health, 2014) recommended changes in the structure of health services to implement multidisciplinary team models for people with co-morbidity in the general population, however the guidance lacks specific detail, simply recommending use of 'multidisciplinary approaches' but not what these should comprise. More recently, the UK National Institute for Health and Care Excellence (National Institute for Health and Care Excellence (National Institute for Health and Care Excellence on the clinical assessment and management of adults with multi-morbidity (multiple long-term conditions). Whilst this lacks specific reference to multidisciplinary team working, they recommended further high-quality research on alternative approaches to organising care for these individuals, particularly in primary care.

#### 2. Research aims

In the absence of formal guidelines regarding how multidisciplinary teams should be operationalised in maternity care (Bick et al., 2014), this mixed methods study aimed to (i) describe, and examine factors influencing, the multidisciplinary team models offered in two National Health Service (NHS) hospitals between maternity and cardiac services before, during and after pregnancy for women with pre-existing cardiac disease (acquired or congenital); (ii) audit the multidisciplinary team care provided for a cohort of women with cardiac disease against best practice recommendations (Royal College of Obstetrics and Gynaecologists (RCOG), 2011; Regitz-Zagrosek et al., 2011; Knight et al., 2014, 2015); and (iii) explore clinicians' and women's experiences of delivering/receiving care within these models.

#### 3. Methods

#### 3.1. Setting & sampling

Data were collected from two inner-city NHS maternity units in the south of England situated within the same local health authority area (Site A and Site B). Sites were purposively selected that served similar obstetric populations. Both had around 6000 births each year, served populations with high levels of social-deprivation, with high proportions of women from black and other ethnic minority groups. The sites

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