Maternal, Newborn and Infant Clinical Outcome Review Programme

MBRRACE-UK
Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

Saving Lives, Improving Mothers' Care

Surveillance of maternal deaths in the UK 2011-13 and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-13

December 2015

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December 2015

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HQIP
Healthcare Quality Improvement Partnership

University of Oxford · University of Leicester · TIMMS · University of Birmingham · Sands stillbirth & neonatal death charity · UCL · NHS Bradford Teaching Hospitals NHS Foundation Trust · npeu National Perinatal Epidemiology Unit

Funding:
The Maternal, Newborn and Infant Clinical Outcome Review programme, delivered by MBRRACE-UK, is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social care division of the Scottish government, the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS), the States of Jersey, Guernsey, and the Isle of Man.

Design by: Sarah Chamberlain and Andy Kirk

Cover artist: Tana West

Printed by: Oxuniprint

This report should be cited as:

Knight M, Tuffnell D, Kenyon S, Shakespeare J, Gray R, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Surveillance of maternal deaths in the UK 2011-13 and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-13. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2015.

ISBN 978-0-9931267-3-4

Individual chapters from this report should be cited using the format of the following example for chapter 3:

Cantwell R, Knight M, Oates M and Shakespeare J. on behalf of the MBRRACE-UK mental health chapter writing group. Lessons on maternal mental health. In Knight M, Tuffnell D, Kenyon S, Shakespeare J, Gray R, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Surveillance of maternal deaths in the UK 2011-13 and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-13. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2015: p22-41.

Foreword

I very much welcome this first MBRRACE-UK report to focus on the psychiatric causes of maternal deaths. The UK was the first country in the world to quantify and examine in detail the reasons why women with mental disorders die in pregnancy and in the postnatal period. Over almost two decades the lessons learned have made stark reading and I commend the work of the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity in bringing the continuing harsh reality of the risks associated with mental disorders to women in the perinatal period to our attention. This new report covers a period of five years where 161 mothers died from psychiatric causes.

The report highlights that care for women before, during and after pregnancy must be seamless across the professions, disciplines and agencies that support and work with women during this period of immense vulnerability. Maternity services, primary care and mental health services need to work together and share information about relevant mental health history to ensure that women receive the appropriate care they need on the basis of an informed risk assessment of their mental health needs. A very clear message in this report is the urgent need to improve training of all the relevant professional groups about perinatal mental illness, and particularly the speed with which women's illness can progress. Crisis and home treatment mental health teams need to address the identified gaps in training regarding the particular distinctive features and risks of perinatal mental illness. Women continue to face huge variation in access to specialist perinatal mental health services (community and in-patient) across unacceptably large areas of the UK despite the evidence that these services may reduce the risk of women dying.

Looking at maternal deaths beyond solely mental health, the predominant theme is that many women who die have multiple morbidities, as well as complex social factors, substance misuse and domestic abuse. Women from vulnerable populations still have a disproportionate risk of dying prematurely, possibly as a result of the multiple health and social challenges they face. This report provides a number of examples of 'tunnel vision' in our clinical thinking – increasing evidence of clinical subspecialisation and an inability to view the woman in a holistic manner and provide for her needs appropriately and effectively. Across the four nations of the UK, the Royal College of Psychiatrists endeavours to work closely with partner organisations and departments of health to promote the well-being of pregnant and postnatal women and to close the gaps in service provision; the College of Psychiatrists in Ireland undertakes a similar role. The College supports the work of the Maternal Mental Health Alliance by working closely with the Royal Colleges of Midwives and Obstetricians and Gynaecologists to improve training and education of all professionals who work with women during this time.

The clear message to us all, whether doctor, midwife, nurse, manager, allied health or social care professional, service planner or policymaker, must be that we need to practice and embed the patient centred care that we all preach. This means providing the kind of care that takes into account the entirety of the woman's health and social needs before, during and after pregnancy. Women remain at high risk throughout the first year after giving birth of death due to mental illness. Therefore, the mental health support and care we provide must be as comprehensive, safe and effective as the physical health care women receive in pregnancy. The need for parity of esteem has never been so self-evident.

Professor Sir Simon Wessely
President of the Royal College of Psychiatrists

Key messages

from the report 2015

MBRRACE-UK
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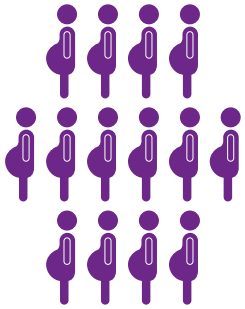
9 women

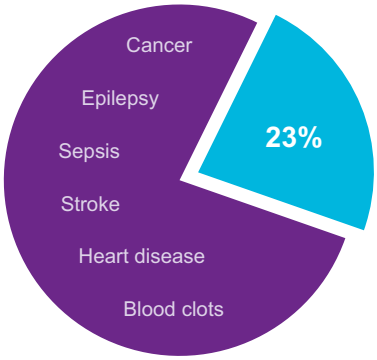
per 100,000 died up to six weeks after giving birth or the end of pregnancy in 2011 - 13



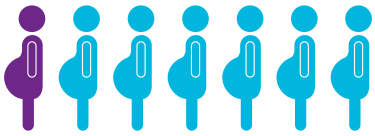
14 more women

per 100,000 died between six weeks and a year after their pregnancy in 2011 - 13

Mental health matters

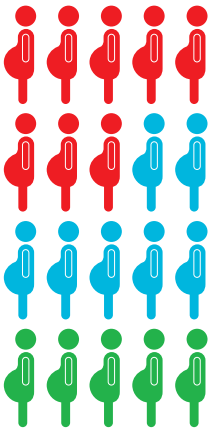


Almost **a quarter** of women who died between six weeks and one year after pregnancy died from **mental-health related causes**



1 in 7 women died by **Suicide**

Specialist perinatal mental health care matters*



If the women who died by suicide became ill today:

- **40%** would not be able to get any specialist perinatal mental health care.
- Only **25%** would get the highest standard of care.

It's OK to tell

The mind changes as well as the body during and after pregnancy.

Women who report:

- New thoughts of violent self harm
- Sudden onset or rapidly worsening mental symptoms
- Persistent feelings of estrangement from their baby

need urgent referral to a specialist perinatal mental health team

*Mapping data from the Maternal Mental Health Alliance (http://everyonesbusiness.org.uk)

Executive Summary

Introduction

The UK Confidential Enquiry into Maternal Deaths (CEMD) has represented a gold standard internationally for detailed investigation and improvement in maternity care for over 60 years. It recognises the importance of learning from every woman's death, during or after pregnancy, not only for the staff and services involved in caring for her, but for the family and friends she leaves behind. This, the second of the Confidential Enquiry into Maternal Deaths annual reports produced by the MBRRACE-UK collaboration, includes data on surveillance of maternal deaths between 2011 and 2013. It also includes Confidential Enquiries for women who died between 2009 and 2013 focusing on lessons on maternal mental health and substance abuse, thrombosis and thromboembolism, caring for women with cancer in pregnancy or postpartum, homicide and domestic abuse, and improvements identified from investigation of the care of women who died between six weeks and one year after the end of pregnancy. In collaboration with MDE Ireland, the report also includes Confidential Enquiries into the deaths of women from these causes in Ireland. Each topic-specific Confidential Enquiry chapter now appears in an annual report once every three years on a cyclical basis.

Surveillance information is included for 575 women who died during or up to one year after the end of pregnancy between 2011 and 2013. The care of 248 women was reviewed in depth for the Confidential Enquiry chapters.

Methods

Maternal deaths are reported to MBRRACE-UK or to MDE Ireland by the staff caring for the women concerned, or through other sources including coroners, procurators fiscal and media reports. In addition, identification of deaths is cross-checked with records from the Office for National Statistics and National Records of Scotland. Full medical records are obtained of all women who die and anonymised prior to undergoing confidential review. The anonymous records are reviewed by a pathologist and clinical epidemiologist, together with an obstetrician or physician as required to establish a woman's cause of death. The care of each woman is then assessed by two obstetricians, two midwives, two pathologists, one or two anaesthetists and other specialist assessors as required, including pairs of psychiatrists, general practitioners, physicians, emergency medicine specialists and intensive care experts. Each woman's care is thus examined by between ten and fifteen expert reviewers. Subsequently the expert reviews of each woman's care are examined by a multidisciplinary writing group to enable the main themes for learning to be drawn out for the MBRRACE-UK report. These recommendations for future care are presented here, alongside a surveillance chapter reporting three years of UK statistical data.

Key areas for action

For Policy-makers, Service Planners and Commissioners, Public Health and Professional Organisations

Perinatal mental health clinical networks should be established to develop local services and clear pathways of care to prevent care being fragmented and uncoordinated. Networks should always include specialist addictions services.

Pregnant and postnatal women who are substance misusers often have complex social and mental health issues and these women need access to assertive outreach care from specialist addictions and specialist mental health services.

Liaison, crisis and home treatment mental health teams require additional support and education in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women.

There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, and during and after pregnancy.

Policy makers and service planners should ensure that there are no barriers in place that prevent clinicians seeking directly the advice and/or involvement of experts in other specialties for women with multiple morbidities, particularly on discharge from maternity care.

Multi-agency local reviews of all women who die from a mental health-related cause at any stage during pregnancy and the first postnatal year should be carried out and should involve all the services that cared for the woman. Similar reviews should be considered for women with complex or multiple morbidities.

For Medical Directors, Clinical Directors, Heads of Midwifery and Clinical Service Managers

Good communication between primary care, mental health and maternity services is critical to good quality care for women with mental ill health, in particular:

- At booking there should be a routine enquiry about a current or past history of mental health problems, which should cover the full range of mental health issues and not just depression.
- Maternity services should ensure that the GP is made aware of a woman's pregnancy and enquire of the GP about the woman's past mental health history.

Mental Health Services should publicise the findings of this report and its procedures widely among mental health staff in order to highlight the messages directly relevant to improving care for pregnant and postpartum women with mental health problems.

All pregnant and postnatal women presenting to the Emergency Department with medical problems should be discussed with a member of the maternity medical team. This should ensure appropriate investigations and treatments for pulmonary embolism are not withheld and prophylaxis is prescribed where appropriate.

Information should be clearly displayed in waiting areas and other suitable places about the support on offer for those affected by domestic violence and abuse. This should include information about relevant local and national helplines. These details should be provided in booking information and hand-held maternity notes.

For Doctors, Midwives and Allied Health Professionals

The following are 'red flag' signs for severe maternal mental illness and require urgent senior psychiatric assessment:

- Recent significant change in mental state or emergence of new symptoms,
- New thoughts or acts of violent self-harm.
- New and persistent expressions of incompetency as a mother or estrangement from the infant.

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. This should be repeated intrapartum or immediately postpartum and if the woman is admitted to hospital or develops other intercurrent problems.

Treat cancer the same in pregnancy as in non-pregnant women. Treating cancer does not usually require early delivery.

Staff in antenatal, postnatal, reproductive care, sexual health, alcohol or drug misuse, mental health, children's and vulnerable adults' services should ask all women whether they have experienced domestic violence and abuse. Women should be given the opportunity to disclose domestic abuse in an environment in which they feel secure.

Causes and trends

Overall there has been a statistically significant decrease in the maternal death rate between 2009-12 and 2011-13 in the UK. Maternal death rates from direct causes continue to decrease, but indirect maternal death rates remain high with no significant change in the rate since 2003. **Coordinated action across a wide range of health services is required to address this problem**.

There were no deaths from influenza in 2012 and 2013, which also contributed to the decrease in the overall rate of maternal death in 2011-13. This is mainly due to a low level of influenza activity in 2012 and 2013 (compared to 2009 and 2010) rather than an increase in the uptake of vaccination among pregnant women. **Increasing immunisation rates in pregnancy against seasonal influenza must remain a public health priority**.

Thrombosis and thromboembolism remains the leading cause of direct maternal death and cardiac disease the leading cause of indirect maternal deaths. Almost a quarter of maternal deaths occurring between six weeks and one year after the end of pregnancy were due to psychiatric causes.

Access to and uptake of antenatal care remains an issue amongst women who died. Only a third of women who died received the nationally recommended level of antenatal care.

Key topic-specific messages for care

Lessons on maternal mental health

The following are 'red flag' signs for severe maternal illness and require urgent senior psychiatric assessment:

- Recent significant change in mental state or emergence of new symptoms,
- New thoughts or acts of violent self-harm,
- New and persistent expressions of incompetency as a mother or estrangement from the infant.

Admission to a mother and baby unit should always be considered where a woman has any of the following:

- rapidly changing mental state,
- suicidal ideation (particularly of a violent nature),
- pervasive guilt or hopelessness,
- significant estrangement from the infant,
- new or persistent beliefs of inadequacy as a mother,
- evidence of psychosis.

Mental health assessments should always include a review of previous history and take into account the findings of recent presentations and escalating patterns of abnormal behaviour.

Loss of a child, either by miscarriage, stillbirth, neonatal death or by the child being taken into care increases vulnerability to mental illness for the mother and she should receive additional monitoring and support.

Partners and other family members may require explanation and education regarding maternal mental illness and its accompanying risks.

Investigations into deaths from psychiatric causes at any stage during pregnancy and the first postnatal year should be carried out and should be multi-agency and include all the services involved in caring for the woman.

Prevention and treatment of thrombosis and thromboembolism

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. This should be repeated intrapartum or immediately postpartum and if the woman is admitted to hospital or develops other intercurrent problems.

Prescription for the entire postnatal course of low molecular weight heparin (LMWH) should be issued in secondary care.

Predictive tools for pulmonary embolism used outside pregnancy to determine the need for radiological investigation, such as the Wells score, are not validated for and should not be used in pregnancy.

Pregnant and postnatal women presenting to the Emergency Department with medical problems should be discussed with a member of the maternity medical team. This should ensure appropriate investigations and treatments for pulmonary embolism are not withheld and prophylaxis is prescribed where appropriate.

Caring for women with cancer in pregnancy or postpartum

Treat cancer the same in pregnancy as in non-pregnant women:

- If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus.
- Treatment for all women with cancer in pregnancy should be the same as for cancer in non-pregnant women, unless there is specific evidence that to do this would cause harm. The same targets for diagnosis and treatment times should apply in pregnant and postpartum women as for non-pregnant women.
- Early multidisciplinary discussions are needed for all pregnant women with a new diagnosis of cancer as well as newly pregnant women with a previous cancer diagnosis. A named individual should be nominated to coordinate care; this is particularly important when care is provided across multiple centres.
- Neurological examination including fundoscopy is mandatory in all women with new onset headaches or headache with atypical symptoms.

Treating cancer does not usually require early delivery:

Iatrogenic preterm delivery is associated with cognitive impairment and other long-term sequelae for the infant and should be avoided wherever possible.

Learning from homicides and women who experienced domestic abuse

Pregnancy and the puerperium represent periods of higher risk of domestic abuse. Any woman reporting a previous history of domestic abuse should therefore be considered at high risk.

Healthcare professionals need to be alert to the symptoms or signs of domestic abuse and women should be given the opportunity to disclose domestic abuse in an environment in which they feel secure.

All health professionals caring for women should be aware of the pathway of care once domestic abuse is disclosed, and escalate to senior staff if necessary.

Pregnant and postpartum women presenting to the emergency department repeatedly and/or with unusual symptoms should be discussed with a member of the maternity team and the GP should be informed.

A named midwife should take responsibility and provide the majority of antenatal care for pregnant women who experience domestic abuse.

The care of any woman murdered during or up to one year after pregnancy should be subject to multi-agency Domestic Homicide Review or equivalent.

Messages for the care of women who died between six weeks and a year after pregnancy

Many of the women who died between six weeks and one year after pregnancy had long-standing and multiple morbidities occurring prior to, during and after pregnancy, and they often led socially complex lives.

Care of these women more than six weeks after birth is currently outside the remit/scope of maternity services, however, there is a clear need for co-ordinated care, including actions for maternity services:

- These women require additional care following discharge from hospital after birth and there should be senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians, midwives and all relevant colleagues.
- The postnatal care plan should include the timing of follow up appointments, which should be arranged with the appropriate services before the woman is discharged and not left to the GP to arrange.
- A comprehensive summary by the senior obstetrician of the maternity care episode should be sent to the GP who should be responsible for co-ordinating care after discharge from maternity services.
- Repeated presentation to the GP, community midwife (while still under maternity services) health visitor or emergency services should be considered a 'red flag' and warrant a thorough assessment by the GP of all of a woman's problems.

Review of a maternal death occurring up to a year after the end of pregnancy should involve all the agencies (including maternity services) who were involved in her care.

There is a need for evidence and practical guidance for the management of women with multiple morbidities and social factors prior to pregnancy, during and after pregnancy.

Conclusions

Almost a quarter of women who died between six weeks and one year after the end of pregnancy died from psychiatric disorders, and this report has identified a number of key messages to improve the care of women with mental illness. For many women who died, the unique features of perinatal mental illness and its rapid escalation were not recognised by staff in general adult mental health services. This reinforces the need for Perinatal Mental Health Networks and the importance of ensuring that all women have access to expert perinatal mental health care. For staff in maternity services and general practice, awareness of 'red flag' symptoms, as well as the pathways of care will help ensure that women get appropriate referral when they need mental health care. Across all of the topic areas reviewed in this report, there was very clear evidence of fragmented care, gaps in care, and a lack of an individual taking overall responsibility for each woman, which is symptomatic of the increasing division of care into sub-specialties. This was particularly evident postnatally. Every member of healthcare staff has a responsibility to ensure that women have appropriate care, even if it is outside their specialty area, and should take personal responsibility for ensuring she has proper follow-up arranged; a letter to the GP will not suffice.

Acknowledgements

It is with grateful thanks that the MBRRACE-UK collaboration would like to acknowledge the contribution of the many healthcare professionals and staff from the health service and other organisations who were involved in the notification of cases, the provision of data and the assessment of individual cases in both the UK and Ireland. Without the generous contribution of their time and expertise it would not have been possible to produce this report. It is only through this collaborative effort that it has been possible to conduct this confidential enquiry and to continue the UK tradition of national self-audit to improve care for women, babies and their families in the future.

We would particularly like to thank all MBRRACE-UK Lead Reporters and other staff in Trusts and Health Boards across the UK and Ireland who provided the information about cases to enable the enquiry to be conducted.

The MBRRACE-UK collaborators would like to express our particular thanks to Professor Jim Neilson, whose contribution to the collaborator group, alongside many years contributing as an assessor, was invaluable in maintaining both the continuity and quality of the Confidential Enquiry into Maternal Deaths.

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Other support staff who assisted on a temporary basis to deal with the backlog of cases:

Nihal Ahmed, Alex Bellenger, Jennifer Collister, Madeleine Crudge, Isobel Daggitt, Amy Lawson, Bethany Lawson, Henry Bailey, Hussein Meyer-Troeltsch, Sharon Mutesi, Julia Pudner, Jacob Reid, Henry Soothill

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- Alison Kirkpatrick, Consultant in Obstetrics and Gynaecology, Frimley Park Hospital NHS Foundation Trust
- Sheila Macphail, Emeritus Consultant Obstetrician, Newcastle Hospitals NHS Foundation Trust
- Hilary MacPherson, Consultant Obstetrician and Gynaecologist, Forth Valley Royal Hospital, Stirlingshire
- Peter McParland, Consultant Obstetrician, National Maternity Hospital, Dublin
- Imogen Montague, Consultant Obstetrician and Gynaecologist, Plymouth Hospitals NHS Trust
- Jane Norman, Professor of Maternal and Fetal Health, University of Edinburgh and NHS Lothian (to November 2013)
- Colm O'Herlihy, Professor of Obstetrics and Gynaecology, University College Dublin
- Roshni Patel, Consultant in Maternal Medicine & Obstetrics, Chelsea and Westminster NHSFT, London
- Sara Paterson-Brown, Consultant Obstetrician, Imperial College Healthcare NHS Trust
- Margaret Ramsay, Consultant in Obstetrics and Fetomaternal Medicine, Nottingham University Hospitals NHS Trust
- Devender Roberts, Consultant Obstetrician and Fetal Medicine, Liverpool Women's NHS Foundation Trust
- Derek Tuffnell, Consultant Obstetrician and Gynaecologist, Bradford Teaching Hospitals NHS Foundation Trust
- Katharine Stanley, Consultant Obstetrician and Gynaecologist, Norfolk and Norwich University Hospitals NHSFT
- Sarah Vause, Consultant in Fetal and Maternal Medicine, St. Mary's Hospital, Manchester

- Gregory Ward, Consultant Obstetrician and Gynaecologist, Croydon Health Services NHS Trust
- Laurence Brown, Consultant Histopathologist, Leicestershire Partnership NHS Trust
- Peter Kelehan, Perinatal and Gynaecological Pathologist, National Maternity Hospital Dublin
- Sebastian Lucas, Professor of Pathology, Guy's and St Thomas' NHS Foundation Trust
- James Lyness, Assistant State Pathologist, State Pathologist's Department, Belfast
- Ula Mahadeva, Consultant Hisopathologist, Guy's and St Thomas' NHS Foundation Trust
- Marjorie Turner, Consultant Forensic Pathologist, University of Glasgow
- Adrian Yoong, Consultant Gynaecological Pathologist, Birmingham Women's NHS Foundation Trust
- Esther Youd, Consultant Histopathologist, Cwm Taf Health Board
- Bernard Clarke, Consultant Cardiologist and Lead for Maternal Cardiology, Central Manchester University Hospitals NHSFT
- Catherine Head, Consultant Cardiologist, Guy's and St Thomas' NHS Foundation Trust
- Rachael James, Consultant Cardiologist, Brighton and Sussex University Hospitals NHS Trust
- Sara Thorne, Consultant Cardiologist and Honorary Senior Lecturer, University Hospitals Birmingham NHS Foundation Trust
- Andrew Kelso, Consultant Neurologist and Honorary Clinical Senior Lecturer, Barts Health NHS Trust
- Adrian Wills, Consultant Neurologist and Honorary Clinical Associate Professor, Nottingham University Hospitals NHS Trust
- Lucy MacKillop, Consultant Obstetric Physician, Oxford University Hospitals NHS Trust
- Catherine Nelson-Piercy, Consultant Obstetric Physician, Guy's and St Thomas' NHS Foundation Trust and Imperial College Healthcare Trust
- Catherine Williamson, Professor in Obstetric Medicine, King's College
- Roch Cantwell, Consultant Perinatal Psychiatrist, NHS Greater Glasgow & Clyde
- Andrew Cairns, Consultant Perinatal Psychiatrist, Northumberland, Tyne and Wear NHSFT
- Tara Lawn, Consultant Perinatal Psychiatrist, East London NHS Foundation Trust
- Ben Nereli, Consultant Perinatal Psychiatrist, South West London & St Georges MH NHS Trust
- Margaret Oates, Consultant Psychiatrist, Nottingham Health Care
- Rowan Pearson, Associate Specialist in Perinatal Psychiatry, Leeds and York Partnerships NHS Foundation Trust
- Olivia Protti, Consultant Perinatal Psychiatrist, East London NHS Foundation Trust
- Anthony McCarthy, Consultant Psychiatrist, National Maternity Hospital, Dublin
- Giles Berrisford, Consultant Psychiatrist, Birmingham and Solihull Mental Health NHSFT
- Fiona Blake, Consultant Psychiatrist, Cambridgeshire and Peterborough NHSFT
- Janine Lynch, Consultant Psychiatrist, Belfast Health and Social Care Trust
- Joanne Fenton, Consultant Psychiatrist, Coombe Women and Infants University Hospital, Dublin
- Paul Sclare, Consultant Psychiatrist, NHS Grampian
- Diana Hulbert, Consultant in Emergency Medicine, University Hospital Southampton NHSFT
- Jim Wardrope, Emeritus Consultant in Emergency Medicine, Sheffield

Office for National Statistics:

Sue Dewane, Christine Coutes, Joanne Evans, Alex Lloyd

National Records of Scotland:

Julie Ramsay, Mary McDonald, Marie Kaye

Information Services Division Scotland, NHS National Services Scotland:

Rachael Wood, Carole Morris, Susan Frame, Jim Chalmers, Kirsten Monteith, Sian Howell

Health Improvement Scotland:

Leslie Marr, Chris Lennox, Jan Warner

Northern Ireland Maternal and Child Health, NSC Public Health Agency:

Heather Reid, Joanne Gluck, Malcolm Buchanan, Tony Crockford

UK Obstetric Surveillance System:

Melanie Workman, Maureen Frostick, Anne Smith, Patsy Spark

The Maternal, Newborn and Infant Clinical Outcome Review Independent Advisory Group:

- Catherine Calderwood (Chair until March 2015), Former National Clinical Director for Maternity and Women's Health for NHS England and Former Medical Advisor for Women and Children's Health for the Scottish Government
- Alan Fenton, Consultant in Neonatal Medicine, Newcastle upon Tyne (member of the IAG from March 2014, chair from September 2015)
- Janice Allister, General Practitioner, Peterborough David Bogod, Consultant Anaesthetist, at Nottingham University Hospitals NHS Trust (member of the IAG until March 2014)
- Zoe Boreland, Midwifery and Children's advisor, Northern Ireland Department of Health, Social Services and Public Safety (member of the IAG from September 2014)
- Cath Broderick, Lay Representative (member of the IAG from October 2013)
- Roch Cantwell, Consultant Psychiatrist, Southern General Hospital, Glasgow (member of the IAG until March 2013)
- Richard Cooke, Professor of Neonatal Medicine, Liverpool Women's Hospital NHS Trust (member of the IAG until October 2012)
- Andy Cole, Chief Executive, Bliss (member of the IAG until March 2014)
- Jacqueline Cornish, National Clinical Director Children, Young People and Transition to Adulthood, NHS England (member of the IAG from March 2014)
- Phillip Cox, Consultant Perinatal Pathologist, Birmingham Women's Hospital
- Caroline Davey, Chief Executive, Bliss (member of the IAG from March 2015)
- Helen Dolk, Professor of Perinatal Epidemiology, Director of the Centre for Maternal, Fetal and Infant Research, Institute for Nursing Research, University of Ulster
- Polly Ferguson, Welsh Government (member of the IAG until March 2013)
- Roshan Fernando, Consultant Anaesthetist and Honorary Senior Lecturer, University College London Hospitals NHS Foundation Trust (member of the IAG from September 2014)
- Melissa Green, Interim Chief Executive, Bliss (member of the IAG from September 2014)
- David James, Clinical Co-director at the National Collaborating Centre for Women's and Children's Health
- Bryan Gill, Consultant in Neonatal Medicine and Medical Director, Leeds (member of the IAG until March 2014)
- Mervi Jokinen, Practice and Standards Development Adviser, Royal College of Midwives
- Jim Livingstone, Northern Ireland Department of Health, Social Services and Public Safety (member of the IAG until March 2013)
- Heather Livingston, Northern Ireland Department of Health, Social Services and Public Safety (member of the IAG until March 2014)
- Heather Mellows, Professional Advisor in Obstetrics, Department of Health (England) (member of the IAG until March 2013)
- Kate McKay, Senior Medical Officer, Scottish Government
- Liz McDonald, Consultant Perinatal Psychiatrist and Clinical Lead for Perinatal Psychiatry, East London Foundation Trust (member of the IAG from October 2013)
- Edward Morris, Consultant in Obstetrics and Gynaecology, Norfolk & Norwich University Hospital and Honorary Senior Lecturer, University of East Anglia
- Heather Payne, Senior Medical Officer for Maternal and Child Health, Welsh Government
- Nim Subhedar, Consultant Neonatologist, Liverpool Women's Hospital NHS Trust (member of the IAG from October 2013)
- Michele Upton, Patient Safety Domain, NHS England (member of the IAG from September 2014)
- Jason Waugh, Consultant and Lead for Obstetric Medicine, Newcastle Upon Tyne.
- David Williams, Consultant Obstetric Physician, The Institute for Women's Health, University College London Hospital
- Paddy Woods, Deputy Chief Medical Officer, Department of Health, Social Services and Public Safety, Northern Ireland (member of the IAG from March 2015)

Healthcare Quality Improvement Partnership:

- Jenny Mooney, Business Manager, Clinical Outcome Review Programmes (to May 2014), Director of Operations, National Clinical Audit and Patient Outcome Programmes (from May 2014)
- Tina Strack, Associate Director, Clinical Outcome
- Lorna Pridmore, Clinical Outcome Review Programmes Facilitator

MBRRACE-UK Third Sector Stakeholder Group and Representatives who Attended Meetings:

- Jane Abbott, BLISS
- Beverley Beech, AIMS
- Jenny Chambers, OC Support
- Debbie Chippington Derrick, Caesarean.org.uk
- Caroline Davey, Bliss
- Jane Denton, Multiple Birth Foundation
- Jane Fisher, ARC
- Pauline Hull, electivecesarean.com
- Penny Kerry, Miscarriage Association
- Helen Kiranne, Bliss
- Beckie Lang, Health Campaigns Tommy's
- Neil Long, Sands
- Sarah McMullen, NCT
- Jane Plumb, Group B Strep Support
- Andrea Priest, Best Beginnings
- Gwynne Rayns, NSPCC
- Keith Reed, TAMBA
- Jean Simons, Lullaby Trust (formerly FSID)
- Lis Thomas, AVMA
- Cheryl Titherly, ARC
- Maureen Treadwell, Birth Trauma Association

MBRRACE-UK Royal College and Professional Association Stakeholder Group and Representatives who Attended Meetings:

- Carmel Bagness, Royal College of Nursing
- Pamela Boyd, Neonatal Nurses Association
- Patrick Cadigan, Royal College of Physicians
- Hilary Cass, Royal College of Paediatrics and Child Health
- Paul Clyburn, Obstetric Anaesthetists Association & Royal College of Anaesthetists
- Sanjeev Deshpande, British Association of Perinatal Medicine
- Denise Evans, Neonatal Nurses Association
- Roshan Fernando, Obstetric Anaesthetists Association & Royal College of Anaesthetists
- Jacque Gerrard, Royal College of Midwives
- Steve Gould, British and Irish Paediatric Pathology Association
- Diane Hulbert, College of Emergency Medicine
- Flora Jessop, British and Irish Paediatric Pathology Association
- Sarah Johnson, Royal College of Obstetricians and Gynaecologists
- Hannah Knight, Royal College of Obstetricians and Gynaecologists
- Lucy Mackillop, Royal College of Physicians
- Lisa Nandi, British Association of Perinatal Medicine
- Catherine Nelson-Piercy, Royal College of Physicians
- Tim Overton, British Maternal Fetal Medicine Society
- Lesley Page, Royal College of Midwives
- Maria Philbin, Royal College of Paediatrics and Child Health
- David Richmond, Royal College of Obstetricians and Gynaecologists
- Jane Sandall, British Maternal Fetal Medicine Society
- Neil Sebire, Royal College of Pathologists
- Lorraine Tinker, Royal College of Nursing

Glossary of terms

AAGBI	Association of Anaesthetists of Great Britain and Ireland
AES	Anti-embolism stockings
ALS	Advanced life support
APT	Anatomical Pathology Technologist
ART	Assisted Reproductive Technology
BMI	Body mass index
BP	Blood pressure
CEMD	Confidential Enquiries into Maternal Deaths
CEMM	Confidential Enquiries into Maternal Morbidity
CESDI	Confidential Enquiry into Stillbirth and Deaths in Infancy
CI	Confidence interval
CMACE	Centre for Maternal and Child Enquiries
COCP	Combined oral contraceptive pill
CORPs	Clinical Outcome Review Programmes
CPD	Continuing professional development
CPR	Cardiopulmonary resuscitation
CT	Computed Tomography
CTPA	Computed Tomography Pulmonary Angiography
CVT	Cerebral Vein Thrombosis
DHR	Domestic Homicide Review
DIC	Disseminated intravascular coagulation
DNA	Deoxyribonucleic acid
ECG	Echocardiogram
DVT	Deep Vein Thrombosis
ECMO	Extracorporeal membrane oxygenation
ENT	Ear, Nose and Throat
EWS	Early warning scores
FFP	Fresh frozen plasma
FIGO	The International Federation of Gynaecology and Obstetrics
FNP	Family Nurse Practitioner
GP	General practitioner
GTN	Glyceryl trinitrate
HDU	High Dependency Unit
HES	Hospital Episode Statistics
HIV	Human Immunodeficiency Virus
HQIP	Healthcare Quality Improvement Partnership
ICD	International Classification of Diseases
IMD	Index of Multiple Deprivation
INR	International Normalised Ratio
ITU	Intensive Therapy Unit
IUD	Intrauterine death
IVF	In Vitro Fertilisation
LMWH	Low Molecular Weight Heparin
MASH	Multi-Agency Safeguarding Hubs
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MBU	Mother and Baby Unit
MDE	Maternal Death Enquiry
MEOWS	Modified Early Obstetric Warning Score
MMR	Maternal mortality ratio
MNI-CORP	Maternal Newborn and Infant Clinical Outcome Review Programme
MR	Magnetic Resonance
MRI	Magnetic Resonance Imaging
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NCISH	National Confidential Enquiry into Suicide and Homicide by People with Mental Illness
NIMACH	Northern Ireland Maternal and Child Health
NRS	National Records Scotland
NSIADs	Non-steroidal anti-inflammatory drugs
OHSS	Ovarian Hyperstimulation Syndrome
ONS	Office for National Statistics
PE	Pulmonary Embolism
PEA	Pulseless electrical activity
PPH	Postpartum Haemorrhage
QOF	Quality Outcome Framework
RCM	Royal College of Midwives
RCOG	Royal College of Obstetricians and Gynaecologists
RR	Risk ratio
RRR	Ratio of relative risks
RTA	Road traffic accident
SADS	Sudden Adult Death Syndrome
SBAR	Situation Background Assessment Recommendation tool
SIGN	Scottish Intercollegiate Guidelines Network
SMD	Severe and multiple deprivation
SUDEP	Sudden unexpected death in epilepsy
SUI	Serious Untoward Incident
T1DM	Type 1 Diabetes Mellitus
TTP	Thrombotic thrombocytopenic purpura
UKDILAS	UK Drugs in Lactation Advisory Service
UKMEC	UK Medical Eligibility Criteria
UKOSS	UK Obstetric Surveillance System
VBAC	Vaginal birth after caesarean section
VTE	Venous thromboembolism
WHO	World Health Organisation

Contents

1. Introduction and methodology

Marian Knight

1.1. The 2015 Saving Lives, Improving Mothers' Care report

This, the second of the Confidential Enquiry into Maternal Deaths and Morbidity reports produced by the MBRRACE-UK collaboration, focuses on lessons on maternal mental health and substance abuse, thrombosis and thromboembolism, caring for women with cancer in pregnancy or postpartum, homicide and domestic abuse, and improvements identified from investigation of the care of women who died between six weeks and one year after the end of pregnancy. It will be seen from the individual chapters that a major theme which recurs throughout this report is vulnerability; many of the women who died were from vulnerable populations, with multiple complex social, medical and mental health factors interacting in their lives and deaths. This is not a new finding for the Confidential Enquiry and begs the question as to why care has not improved and why vulnerable women continue to die disproportionately. This report identifies a number of key actions to be taken forward, but there are areas of care, such as postnatal care, which need a complete rethink; this is beyond the scope of this report.

The UK Confidential Enquiry into Maternal Deaths (CEMD) has represented a gold standard internationally for detailed investigation and improvement in maternity care for over 60 years. It recognises the importance of learning from every woman's death, during or after pregnancy, not only for the staff and services involved in caring for her, but for the family and friends she leaves behind. The key aspects of the work contained in this 2015 report, which we believe should set an international precedent, include the full investigation of all suicides of women during or up to one year after pregnancy, irrespective of whether they are classified as following puerperal psychosis or postnatal depressive illness; and the detailed investigation of late maternal deaths, which is of particular relevance to high resource countries, where women may be kept alive by supportive therapies for many weeks or months after their pregnancy-related or pregnancy-exacerbated illness. These detailed investigations, whilst based on review of the care of only the relatively small number of women who died have nevertheless identified major gaps in care and, in particular, the continuing division of healthcare services and healthcare worker mentality into 'silos' with no single individual taking responsibility for holistic care.

Nonetheless, the 2015 report contains some evidence of positive change since the 2014 report. Maternal influenza-related deaths have significantly decreased, maternal deaths from pre-eclampsia and eclampsia continue to be the fewest ever, with only 1 in every 400,000 women giving birth in the UK today dying from pregnancy-related hypertensive disorders. It is also encouraging to see a number of ongoing actions in response to the 2014 report. Some examples include: a green-top guideline on epilepsy in pregnancy which has been developed and is currently under revision following consultation; information from the 2015 report was used by Public Health England to develop briefings for local teams on influenza vaccination, and by NHS Education for Scotland to develop a maternal sepsis e-learning module; progress is also under way to develop a tool for local reviews of maternal deaths.

Readers will be aware that the innovation introduced in the last report was to include confidential enquiries into maternal morbidity as well as mortality. We had planned to include review of the care of women who had survived maternal psychosis in this report, but unfortunately delays in obtaining the permissions to allow us to identify these women have meant that we are not able to include this morbidity enquiry in this report. We hope to include these reviews in the 2016 report, alongside the 2016 morbidity confidential enquiry into the care of pregnant women with artificial heart valves.

A further new innovation was the requirement for annual reporting and topic-specific confidential enquiry chapters, which caused some confusion. With this second annual report, hopefully the pattern of reporting will become clearer, but just as a reminder, the programme now requires the production of annual CEMD reports. Reports were previously produced on a triennial basis because the number of maternal deaths from individual causes is small, and thus three years' worth of data is required to identify consistent lessons learned for future care and to maintain anonymity and confidentiality. Clearly the need to undertake annual reporting does not change this requirement, therefore, each topic-specific chapter which appeared in the previous triennial report now appears in an annual report once every three years on a cyclical basis, alongside a

surveillance chapter reporting three years of UK statistical data. Statistical data from Ireland are produced separately by MDE Ireland. The topics to be included in the 2015 to 2017 MBRRACE-UK reports are as follows:

- **2015 (this report):** Surveillance data on UK maternal deaths from 2011-13. Confidential Enquiry reports on deaths from psychiatric causes, deaths due to thrombosis and thromboembolism, malignancy, homicides and late deaths occurring in the UK and Ireland.
- **2016:** Surveillance data on UK maternal deaths from 2012-14. Confidential Enquiry reports on deaths and severe morbidity from cardiac causes, severe morbidity from psychiatric causes, deaths from pre-eclampsia and eclampsia and related causes and deaths in early pregnancy occurring in the UK and Ireland.
- **2017:** Surveillance data on UK maternal deaths from 2013-15. Confidential Enquiry reports on severe morbidity from epilepsy, deaths from sepsis, haemorrhage, amniotic fluid embolism (AFE), anaesthesia, neurological, respiratory, endocrine and other indirect causes occurring in the UK and Ireland.

1.2. The MBRRACE-UK Confidential Enquiries into Maternal Deaths Methods

Identifying Maternal Deaths

The deaths of women during or after pregnancy are identified through a variety of sources. The majority are notified to the MBRRACE-UK office directly from the unit in which the maternal death occurred. We request that all such deaths are notified within one week of the death occurring. Others are notified from a variety of individuals such as Coroners/Procurators Fiscal or pathologists, Local Supervising Authority Midwifery Officers and members of the public. Reports are also identified by the central MBRRACE-UK team from the media, for example, when the results of inquests are reported.

Ascertainment of deaths is cross-checked with records from the Office for National Statistics and National Records of Scotland. Both these sources provide details of registered deaths of any women in which pregnancy, or a pregnancy-specific cause, is listed on the death certificate. In addition, maternal details in birth records are linked to deaths of women of reproductive age occurring over the following 12 months, in order to identify maternal deaths where pregnancy or pregnancy-specific causes are not listed on the death certificate. The deaths identified from these additional sources are then compared with the deaths reported to MBRRACE-UK and when an unreported death is identified, the hospitals where the birth and death occurred are contacted and asked to provide records.

Collecting Information about Maternal Deaths

Following the report of a maternal death, a notification pack is sent to the unit in which the death has occurred (Figure 1.1). This includes a surveillance form to collect basic demographic and clinical details about the death, together with a form requesting the contact details of the clinicians involved in managing the woman's care. The hospital MBRRACE-UK contact is asked to return the completed surveillance form together with the details of the local clinicians within one month of the death occurring. The hospital MBRRACE-UK contact is also asked to return a full photocopy of the woman's medical records.

After these documents have been returned, the MBRRACE-UK team send out local clinicians report forms to the clinical staff involved in the woman's care. These ask for the staff perspectives on the care of the woman, and ask them to identify any lessons learned for future care. These documents, together with the woman's medical records, are fully anonymised, scanned and uploaded onto the MBRRACE-UK secure viewing system for independent assessment by MBRRACE-UK trained assessors. Our aim is to have all data complete and ready for assessment by three months from the date of a woman's death.

In addition to case records from the unit in which the woman died, the MBRRACE-UK team also seek records from other units which cared for her, including units where she delivered as well as had any other antenatal care. In addition, they seek copies of the post-mortem report, either from the hospital pathologist or from the Coroner/Procurator Fiscal. Units are also asked to return a copy of their local review (Serious Untoward Incident review, Root Cause Analysis or similar) where this has been undertaken to provide identified messages for future care at a local level.

Identifiable information about maternal deaths in England, Scotland and Wales is collected directly by the MBRRACE-UK office in Oxford. Privacy issues in Northern Ireland are such that identifiable information about women who have died during or

after pregnancy cannot be transferred out of the Province. All the case records and surveillance data are therefore collected by the staff of the Northern Ireland Maternal and Child Health (NIMACH) office of the Public Health Agency of Northern Ireland. Fully anonymised records are then transferred securely to the MBRRACE-UK office in Oxford for analysis and expert review.

The surveillance information about each death is double-entered into a customised database. Queries about missing or unclear data items are sent back to units to ensure that the data are of high quality and complete. In addition, some data items may be extracted directly from the maternal death records by MBRRACE-UK team staff. Once the data are complete, a dataset is extracted and cleaned prior to analysis by the MBRRACE-UK epidemiology team based in the National Perinatal Epidemiology Unit, University of Oxford.

The Maternal Death Enquiry Ireland

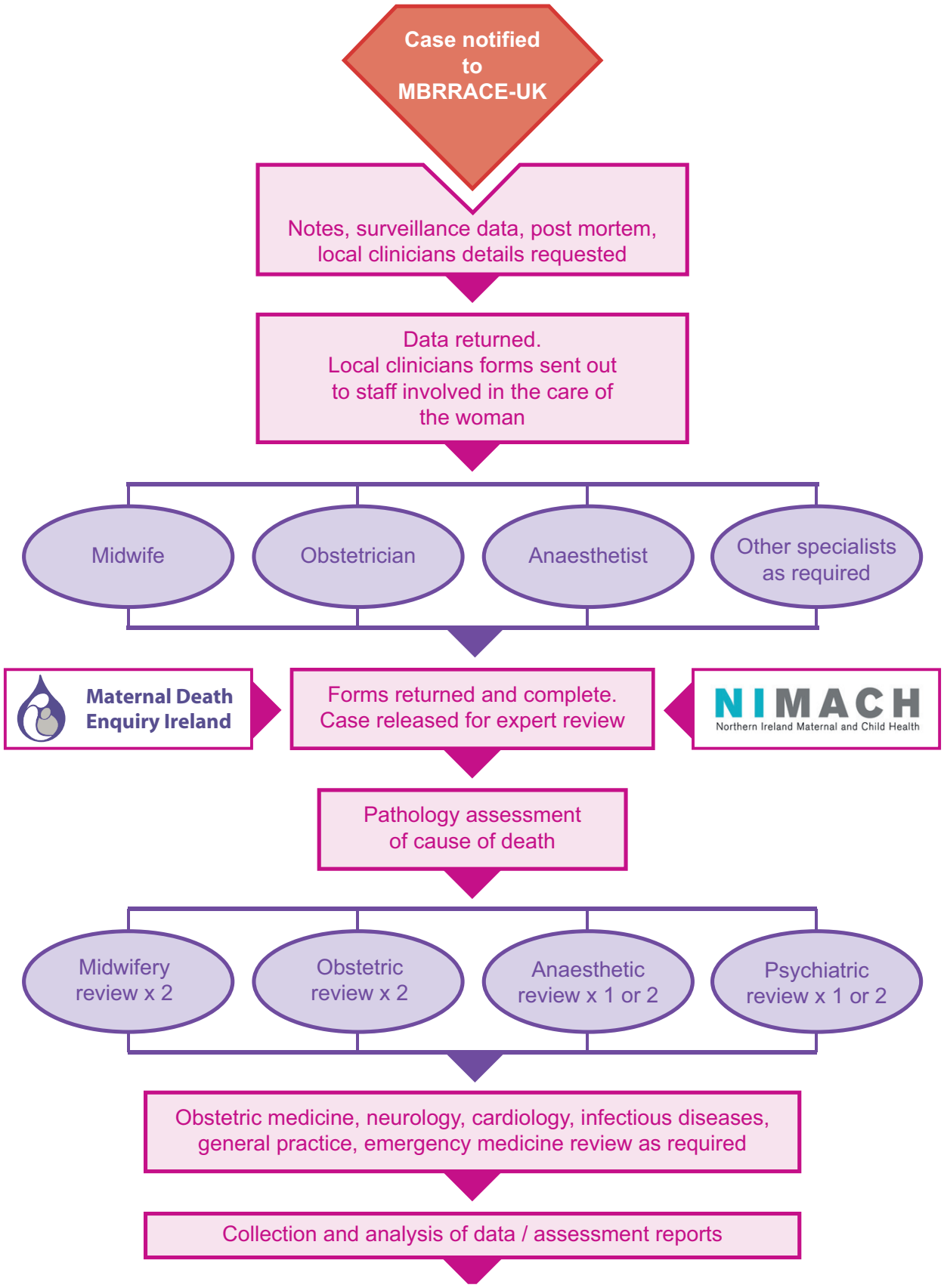
Deaths from the UK and Ireland are assessed together in a joint Confidential Enquiry process. The Maternal Death Enquiry (MDE) Ireland was established in 2009 with the remit to carry out surveillance and Confidential Enquiries into maternal deaths in Ireland (Confidential Maternal Death Enquiry in Ireland 2012). In order to enhance the generalisability of the messages for care, whilst maintaining confidentiality and anonymity, maternal deaths occurring in Ireland are assessed alongside UK deaths using the same processes. Expert assessors from the Irish Republic have joined the pool of UK assessors and contribute to assessment in the same way as UK assessors. Data for Ireland are collected by staff from the MDE Ireland office in Cork; fully anonymised records are then transferred to the UK MBRRACE-UK office for upload onto the secure viewing system. MDE Ireland continues to analyse and publish surveillance data for Ireland independently (O'Hare, Manning et al. 2015); surveillance information for the Republic of Ireland is not included in this report and the trends described in Chapter 2 refer only to the UK. The number of deaths reported in each Confidential Enquiry chapter will thus differ from the number recorded in the surveillance chapter due to the inclusion in the Confidential Enquiry of deaths from the Republic of Ireland, as well as deaths occurring in 2009-10 and selected late maternal deaths.

Expert Review

MBRRACE-UK has over 100 assessors from various different speciality groups, including anaesthetics, intensive care, obstetrics, midwifery, psychiatry, pathology, general practice, emergency medicine and various medical specialities, including obstetric physicians, cardiologists, infectious diseases physicians and neurologists. Assessors were appointed in a selection process organised by the relevant Royal Colleges or professional associations, which required specific skills and experience; all are volunteers and do not receive financial remuneration for their work, although they are able to classify their MBRRACE-UK work as part of continuing professional development (CPD). All assessors have undergone a training process and are provided with guidance detailing relevant standards of care against which deaths are assessed. Where possible, the guidance is drawn from national sources such as the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) or professional organisations such as the Royal College of Obstetricians and Gynaecologists (RCOG) and the Association of Anaesthetists of Great Britain and Ireland (AAGBI).

Once the complete records concerning a particular woman have been received, the anonymous records are reviewed by a pathologist and clinical epidemiologist, together with an obstetrician or physician as required. This establishes the most likely cause of the woman's death and allows for her records to be allocated to the appropriate speciality assessors. The care of each woman is then assessed by two obstetricians, two midwives, two pathologists, one or two anaesthetists and other specialist assessors as required, including pairs of psychiatrists, general practitioners, physicians, emergency medicine specialists and intensive care experts. Each woman's care is thus examined by between ten and fifteen expert reviewers. Each primary assessor completes an independent review of the woman's care, highlighting the lessons to be learned to improve care in the future. This is checked by a second assessor in the relevant specialty. Expert assessors are located in all areas of the UK and Ireland; to maintain anonymity, assessors are only allocated reviews of the care of women who have died outside their region or nation. The assessment process and all individual findings are strictly confidential; all assessors are required to sign a confidentiality agreement. Expert assessors give their opinion on the quality of care according to the three criteria given in Box 1.1.

Figure 1.1: MBRRACE-UK Data Collection and Assessment Processes



Box 1.1: Assessment of Quality of Care

- *Good care; no improvements identified*
- *Improvements in care* identified which would have made no difference to the outcome*
- *Improvements in care* identified which may have made a difference to the outcome*

*Improvements in care are interpreted to include adherence to guidelines, where these exist and have not been followed, as well as other improvements which would normally be considered part of good care, where no formal guidelines exist.

Assessors are also asked to identify whether any woman's death should be notified to the Healthcare Quality Improvement Partnership (HQIP), which has a standard protocol for all the Clinical Outcome Review Programmes to escalate major concerns about care where it is clear these concerns have not been addressed at a local level. Deaths are notified to HQIP if there is consensus among assessors that they meet one of the following criteria (Box 1.2):

Box 1.2: Concerns escalated to HQIP – standard procedure for all Clinical Outcome Review Programmes

- *Death (child or adult) attributable to abuse or neglect, in any setting, but no indication of cross agency involvement (i.e. no mention of safeguarding, social services, police or Local Safeguarding Children Board).*
- *Staff member displaying:*
  - *Abusive behaviour (including allegations of sexual assault)*
  - *Serious professional misconduct*
  - *Dangerous lack of competency*
  - ***But** it is not clear if the incident has been reported to senior staff*
- *Standards in care that indicate a dysfunctional or dangerous department or organisation, or grossly inadequate service provision.*

Reviewing the evidence and reaching conclusions

Once data collection is complete and all women's care has undergone expert assessment, chapter writing groups are convened. These multi-disciplinary groups consist of representatives from all the different relevant specialist assessor groups. Each chapter writing group discusses the care of all of the women who died from a specific cause of death. Initially the cause of death and classification of care is discussed to ensure that all deaths are appropriately classified; subsequently the expert reviews of each woman's care are examined to enable the main themes for learning to be drawn out for the MBRRACE report. Lead members of each chapter-writing group then draft the initial chapter, which is then edited by Marian Knight and reviewed by all the other group members and editors as well as external peer reviewers if required, prior to reaching a final agreed version. Where possible, recommendations are linked to national guidance from organisations such as NICE.

Definitions and statistical methods

A maternal death is defined internationally as a death of a woman during or up to six weeks (42 days) after the end of pregnancy (whether the pregnancy ended by termination, miscarriage or a birth, or was an ectopic pregnancy) through causes associated with, or exacerbated by, pregnancy (World Health Organisation 2010). A late maternal death is one which occurs more than six weeks but less than one year after the end of pregnancy. Deaths can be further subdivided on the basis of cause into: direct deaths, from pregnancy-specific causes such as pre-eclampsia; indirect deaths, from other medical conditions made worse by pregnancy such as cardiac disease; or coincidental deaths, where the cause is considered to be unrelated to pregnancy, such as road traffic accidents. These definitions are summarised in Box 1.3.

Box 1.3. Definitions of maternal deaths (World Health Organisation 2010)

Maternal death	Death of a women 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.
Direct	Deaths resulting from obstetric complications of the pregnant state (pregnancy, labour and puerperium), from interventions, omissions, incorrect treatment or from a chain of events resulting from any of the above.
Indirect	Deaths resulting from previous existing disease, or disease that developed during pregnancy and which was not the result of direct obstetric causes, but which was aggravated by the physiological effects of pregnancy.
Late	Deaths occurring between 42 days and 1 year after the end of pregnancy* that are the result of Direct or Indirect maternal causes.
Coincidental†	Deaths from unrelated causes which happen to occur in pregnancy or the puerperium.

*Includes giving birth, ectopic pregnancy, miscarriage or termination of pregnancy.

†Termed "Fortuitous" in the International Classification of Diseases (ICD)

For the purposes of MBRRACE-UK and preceding UK Confidential Enquiries, maternal mortality rates with 95% confidence intervals are calculated using national data on the number of maternities (women giving birth at or beyond 24 weeks gestation) as the denominator. This differs from quoted standard international maternal mortality ratios (MMR) which use live births as the denominator; a calculated MMR is provided for comparison purposes. Total maternities for the UK for the period 2009 to 2013 were obtained from the annually reported birth data for England and Wales (Office for National Statistics 2013), Scotland (General Register Office for Scotland 2013) and Northern Ireland (Northern Ireland Statistics and Research Agency 2013). These data were used to calculate age-specific and country of birth-specific mortality rates and relative risks. As previously (Lewis, Cantwell et al. 2011), Hospital Episode Statistics (HES) maternity data for England, were used to estimate the denominators for ethnic groups and quintiles of deprivation, and hence to derive estimated mortality rates and relative risks by ethnic and socioeconomic groups in England. Maternities for which ethnicity was not stated were included in the 'white European' group because the re-distributed proportions matched with the estimated ethnic profiles in the UK population census (Health & Social Care Information Centre 2006).

The characteristics of women who die are tabulated and compared where possible with national population data. Characteristics are also compared with other population based data sources, such as from existing UK Obstetric Surveillance System (UKOSS) studies (Nair, Kurinczuk et al. 2015) if there are no other possible sources of comparative data.

A non-parametric test for trend across ordered groups was used to investigate the change in three-yearly maternal mortality rates over time and maximum likelihood estimation was used to analyses the annual change in the rate of specific causes of death from 2009-13. Risk ratios with 95% confidence intervals were calculated to compare maternal death rates between groups of women. The data were analysed in STATA version 13 (Statacorp).

2. Maternal Mortality in the UK 2011-13: Surveillance and Epidemiology

Manisha Nair and Marian Knight

2.1. Key points

Overall there has been a statistically significant decrease in the maternal death rate between 2009-12 and 2011-13 in the UK.

Maternal deaths from direct causes continue to decrease, but indirect maternal deaths remain high with no significant change in the rate since 2003. Coordinated action across a wide range of health services is required to address this problem.

There were no deaths from influenza in 2012 and 2013, which also contributed to the decrease in the overall rate of maternal death in 2011-13. This is mainly due to a low level of influenza activity in 2012 and 2013 (compared to 2009 and 2010) rather than an increase in the uptake of vaccination among pregnant women. Increasing immunisation rates in pregnancy against seasonal influenza must remain a public health priority.

Thrombosis and thromboembolism remains the leading cause of direct maternal death and cardiac disease the leading cause of indirect maternal deaths.

Almost a quarter of maternal deaths occurring between six weeks and one year after the end of pregnancy are due to psychiatric causes.

Access to antenatal care remains an issue amongst women who died. Only a third of women who died received the nationally recommended level of antenatal care.

2.2. Causes and trends

Overall, 240 women died in 2011-13 during or within 42 days of the end of pregnancy in the UK. The deaths of 26 women were classified as coincidental. Thus in this triennium there were 214 deaths due to direct and indirect causes among 2,373,213 maternities, a maternal death rate of 9.02 per 100,000 maternities (95% CI 7.85–10.31). This compares to a rate of 10.12 per 100,000 maternities (95% CI 8.89–11.47) in 2010-12. As in the 2014 report, information on deaths from the Republic of Ireland is not included in this chapter and therefore rates and numbers presented here are comparable with all previous UK reports.

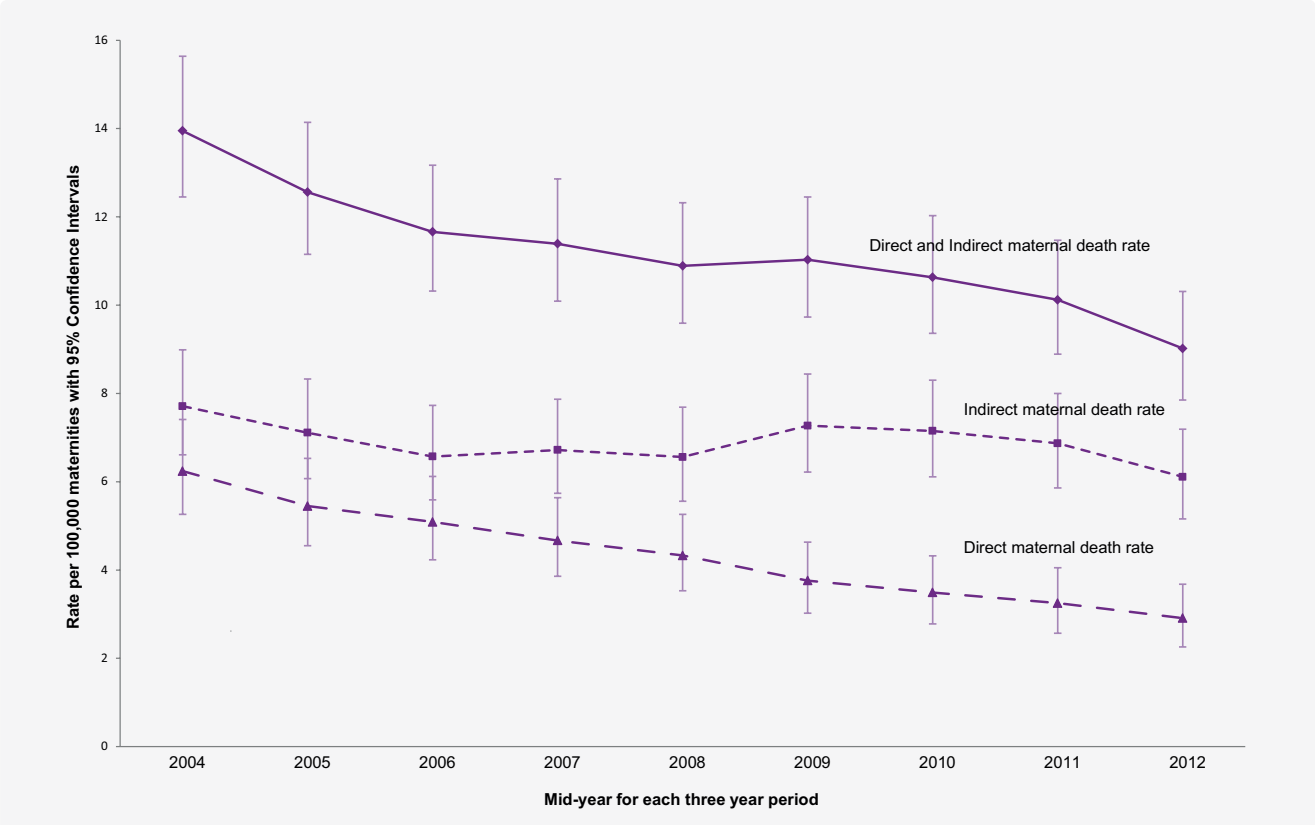
Table 2.1 and Figure 2.1 show rolling three-yearly maternal death rates since 2003. The decreasing trend in maternal death rates has continued with overall a 35% (95% CI 23%-46%) decrease in maternal deaths between 2003-05 and 2011-13 (rate ratio (RR) 0.65; 95% CI 0.54-0.77 comparing 2003-5 with 2011-13; p=0.005 for trend over time). The direct maternal death rate has decreased by more than half since 2003-05 with a RR of 0.47 (95% CI 0.34-0.63) when comparing 2011-13 with 2003-05; p=0.005 for trend over time. Consistent with the previous report, there was no statistically significant decrease in the rate of indirect maternal deaths (RR 0.79, 95% CI 0.63-1.00 when comparing 2011-13 with 2003-05; p=0.278 for trend over time).

Table 2.1: Rolling three-year average Direct and Indirect maternal mortality rates per 100,000 maternities; UK 2003-13

3-year period	Total UK maternities	Direct deaths			Indirect deaths			Total Direct and Indirect deaths		
		n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
2003–05	2 114 004	132	6.24	5.26–7.41	163	7.71	6.61–8.99	295	13.95	12.45–15.64
2004–06	2 165 909	118	5.45	4.55–6.53	154	7.11	6.07–8.33	272	12.56	11.15–14.14
2005–07	2 220 979	113	5.09	4.23–6.12	146	6.57	5.59–7.73	259	11.66	10.32–13.17
2006–08	2 291 493	107	4.67	3.86–5.64	154	6.72	5.74–7.87	261	11.39	10.09–12.86
2007–09	2 331 835	101	4.33	3.53–5.26	153	6.56	5.56–7.69	254	10.89	9.59–12.32
2008–10	2 366 082	89	3.76	3.02–4.63	172	7.27	6.22–8.44	261	11.03	9.73–12.45
2009–11	2 379 014	83	3.49	2.78–4.32	170	7.15	6.11–8.30	253	10.63	9.36–12.03
2010–12	2 401 624	78	3.25	2.57–4.05	165	6.87	5.86–8.00	243	10.12	8.89–11.47
2011–13	2 373 213	69	2.91	2.26–3.68	145	6.11	5.16–7.19	214	9.02	7.85–10.31

Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Figure 2.1: Direct and Indirect maternal mortality rates per 100 000 maternities; rolling three year average rates 2003-2013



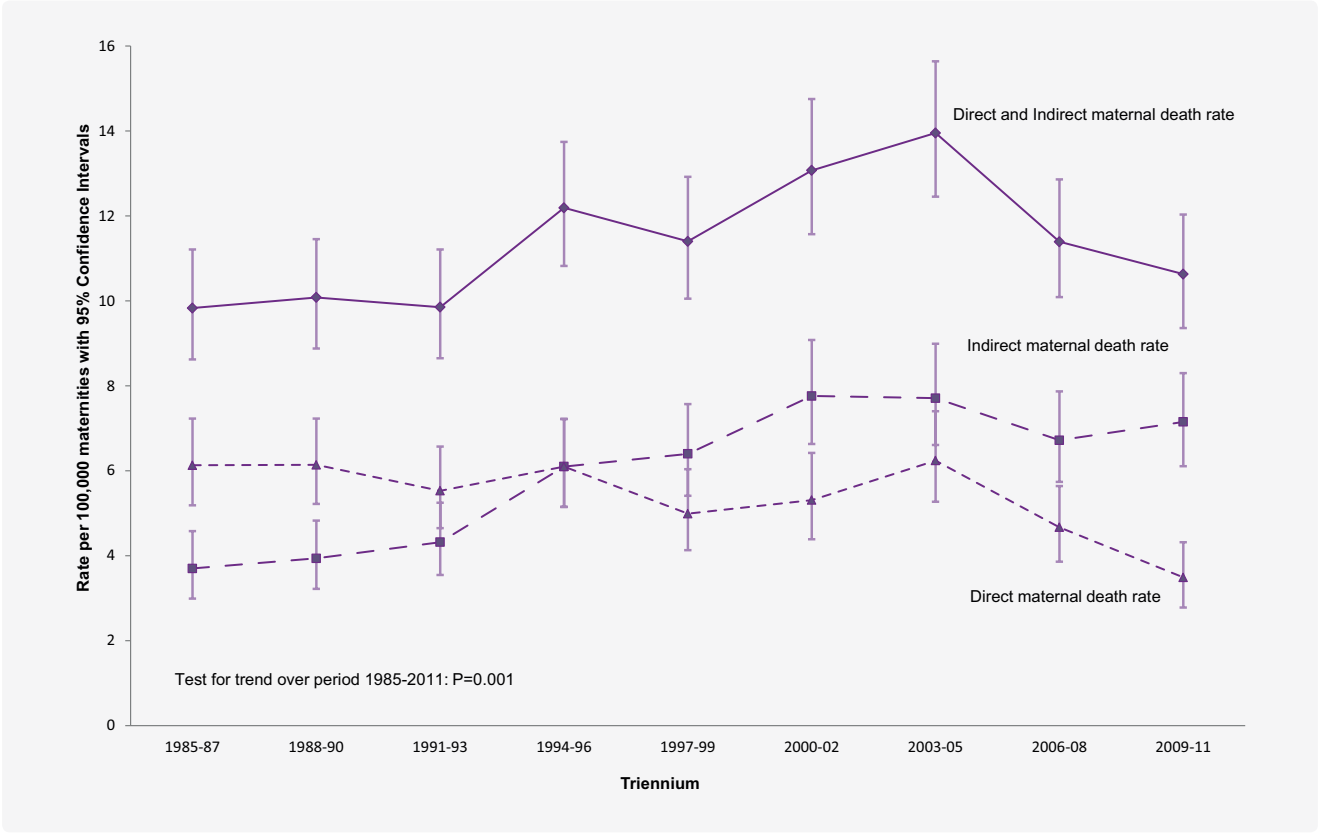
Sources: CMACE, MBRRACE-UK

The trends in triennial rates since 1985-87 are shown in Table 2.2 and Figure 2.2. Note that only rates for 2009-11 are included for consistency with previous reports which included triennial rates, therefore, the information has not changed since the 2014 report. The information will be updated in the 2016 report with rates for 2012-14.

Table 2.2: Direct and Indirect maternal deaths and mortality rates per 100,000 maternities by triennium, UK 1985-2011

Triennium	Direct deaths recorded			Indirect deaths recorded			Total Direct and Indirect deaths recorded		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
1985–87	139	6.13	5.19–7.23	84	3.70	2.99–4.58	223	9.83	8.62–11.21
1988–90	145	6.14	5.22–7.23	93	3.94	3.22–4.83	238	10.08	8.88–11.45
1991–93	128	5.53	4.65–6.57	100	4.32	3.55–5.25	228	9.85	8.65–11.21
1994–96	134	6.10	5.15–7.22	134	6.10	5.15–7.22	268	12.19	10.82–13.74
1997–99	106	4.99	4.13–6.04	136	6.40	5.41–7.57	242	11.40	10.05–12.92
2000–02	106	5.31	4.39–6.42	155	7.76	6.63–9.08	261	13.07	11.57–14.75
2003–05	132	6.24	5.27–7.40	163	7.71	6.61–8.99	295	13.95	12.45–15.64
2006–08	107	4.67	3.86–5.64	154	6.72	5.74–7.87	261	11.39	10.09–12.86
2009–11	83	3.49	2.78–4.32	170	7.15	6.11–8.30	253	10.63	9.36–12.03

Figure 2.2: Direct and Indirect maternal mortality rates per 100,000 maternities; UK: 1985-2011



Sources: CMACE, MBRRACE-UK

We investigated further the decrease in the maternal death rate in 2011-13 compared to previous years in order to identify the key drivers, and to rule out any possibility that the observed decrease was due to failure to identify some women's deaths. In addition to the decrease in direct maternal deaths from all causes, there was a statistically significant decrease in deaths due to influenza, with a 67% decrease (RR 0.33, 95% CI 0.14-0.78) when comparing 2011-13 with 2009-10; p<0.001 for trend over time. This may be due to a lower level of influenza activity in 2011-13 compared to 2009 and 2010 when there was a major impact from pandemic 2009/AH1N1 influenza (Public Health

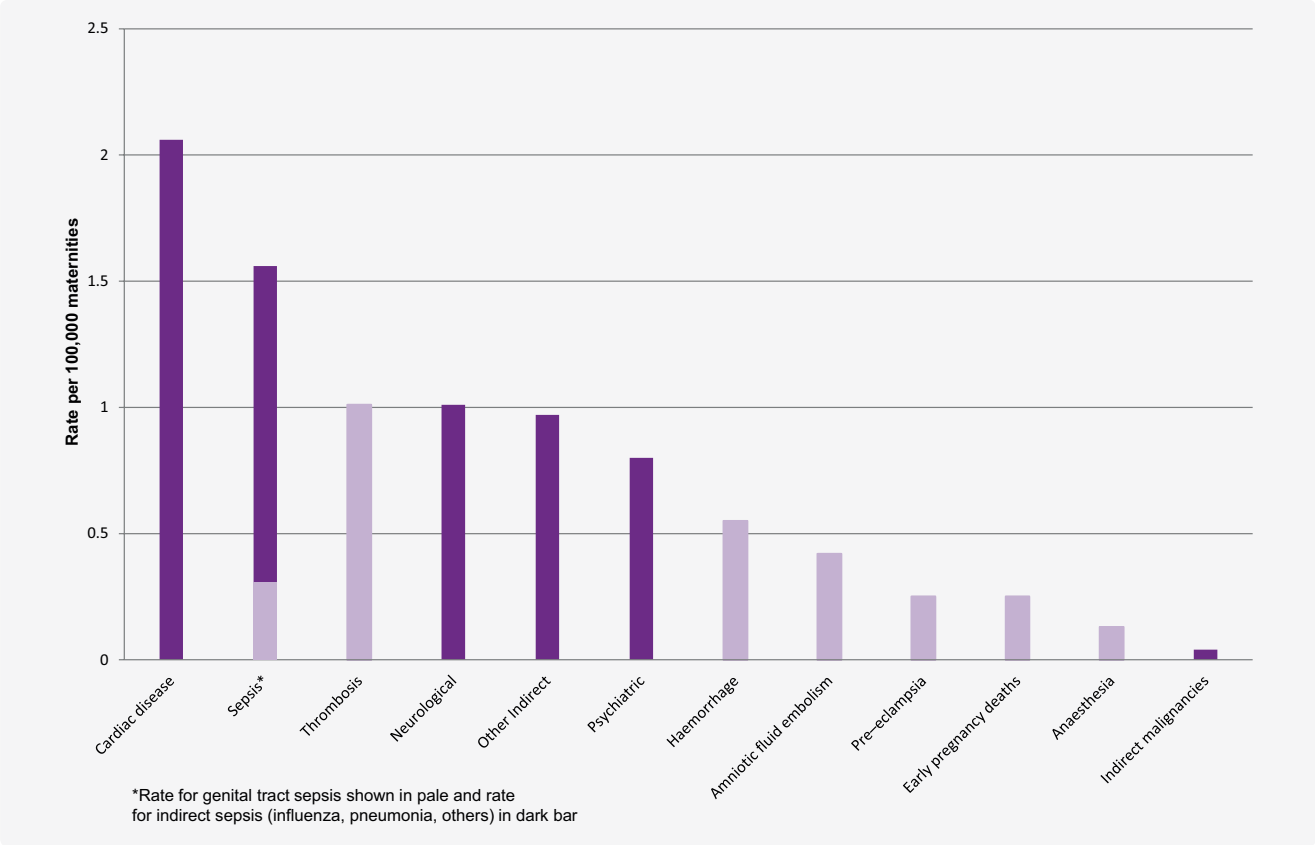
England 2014). The uptake of vaccination among all pregnant women has increased by varying degrees across the UK, in England, vaccination uptake increased from 27% in 2011-12 to 40% in 2013-14; in Scotland from 41% in 2011-12 to 49% in 2013-14; in Northern Ireland the uptake was 58% for both time-periods, and in Wales the uptake increased from 32% in 2011-12 to 71% in 2013-14 (Public Health England 2013, Public Health England 2014). The maternal death rates due to influenza are presented in table 2.3. There was no statistically significant change in the rates of maternal death due to other causes; a detailed discussion of the individual causes is presented below.

The only maternal deaths which are unlikely to be identified through the additional linkage processes used by MBRRACE-UK to check case ascertainment are deaths of women after early miscarriage. A previous miscarriage may not be noted on the woman's death certificate, and therefore her death may not be identified as a maternal death. Identifying such women's deaths is therefore dependent on a good network of reporting clinicians and others. In order to examine whether under-ascertainment of these women's deaths was responsible for the observed decrease, we compared the rate of maternal death following miscarriage at less than 20 weeks gestation in 2011-13 with the rate in 2006-8. There was no statistically significant difference, therefore under-ascertainment of maternal deaths following miscarriage is unlikely to account for the observed decrease in the maternal death rate in the UK.

Deaths due to individual causes

Maternal deaths by cause from 2009-13 are shown in Table 2.3 and Figure 2.3. Rolling three years rates for individual causes are presented for three triennial reporting periods (2009-11, 2010-12 and 2011-13).

Figure 2.3: Maternal mortality by cause 2011-13



Dark bars indicate indirect causes of death, pale bars show direct causes of death; Source: MBRRACE-UK

Table 2.3: Maternal mortality rates by cause, per 100,000 maternities, 2009 to 2013

Cause of death	2009-11			2010-12			2011-13		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
All Direct and Indirect deaths	253	10.63	9.36–12.03	243	10.12	8.89–11.47	214	9.02	7.85–10.31
Direct deaths									
*Sepsis**	15	0.63	0.35–1.04	12	0.50	0.26–0.87	7	0.29	0.12–0.61
Pre-eclampsia and eclampsia	10	0.42	0.2–0.77	9	0.38	0.18–0.71	6	0.25	0.09–0.55
Thrombosis and thromboembolism	30	1.26	0.85–1.80	26	1.08	0.71–1.59	24	1.01	0.65–1.5
Amniotic fluid embolism	7	0.29	0.12–0.61	8	0.33	0.14–0.66	10	0.42	0.20–0.78
Early pregnancy deaths	4	0.17	0.05–0.43	8	0.33	0.14–0.66	6	0.25	0.09–0.55
Haemorrhage	14	0.59	0.32–0.99	11	0.46	0.23–0.82	13	0.55	0.29–0.94
Anaesthesia	3	0.12	0.03–0.37	4	0.17	0.05–0.43	3	0.13	0.03–0.37
All Direct	83	3.49	2.78–4.32	78	3.25	2.57–4.05	69	2.91	2.26–3.68
Indirect									
Cardiac disease	51	2.14	1.60–2.82	54	2.25	1.69–2.93	49	2.06	1.53–2.73
Indirect Sepsis - Influenza	27	1.13	0.75–1.65	13	0.54	0.29–0.93	9	0.38	0.17–0.72
Indirect Sepsis – Pneumonia/ others	16	0.67	0.38–1.09	22	0.92	0.57–1.39	21	0.89	0.55–1.35
Other Indirect causes	29	1.22	0.82–1.75	26	1.08	0.71–1.59	22	0.93	0.58–1.40
Indirect neurological conditions	30	1.26	0.85–1.80	31	1.29	0.88–1.83	24	1.01	0.65–1.50
Psychiatric causes	13	0.55	0.29–0.93	16	0.67	0.38–1.08	19	0.80	0.48–1.25
Indirect malignancies	4	0.17	0.05–0.45	3	0.13	0.03–0.37	1	0.04	0.001–0.24
All Indirect	170	7.15	6.11–8.30	165	6.87	5.86–8.00	145	6.11	5.16–7.19
Coincidental deaths	23	0.98	0.61–1.45	26	1.08	0.71–1.59	26	1.10	0.72–1.61
Late deaths	325	13.66	12.22–15.33	313	13.03	11.63–14.56	335	14.12	12.64–15.71

*Genital tract sepsis deaths only, including early pregnancy deaths as the result of genital tract sepsis. Other deaths from infectious causes are classified under indirect causes.

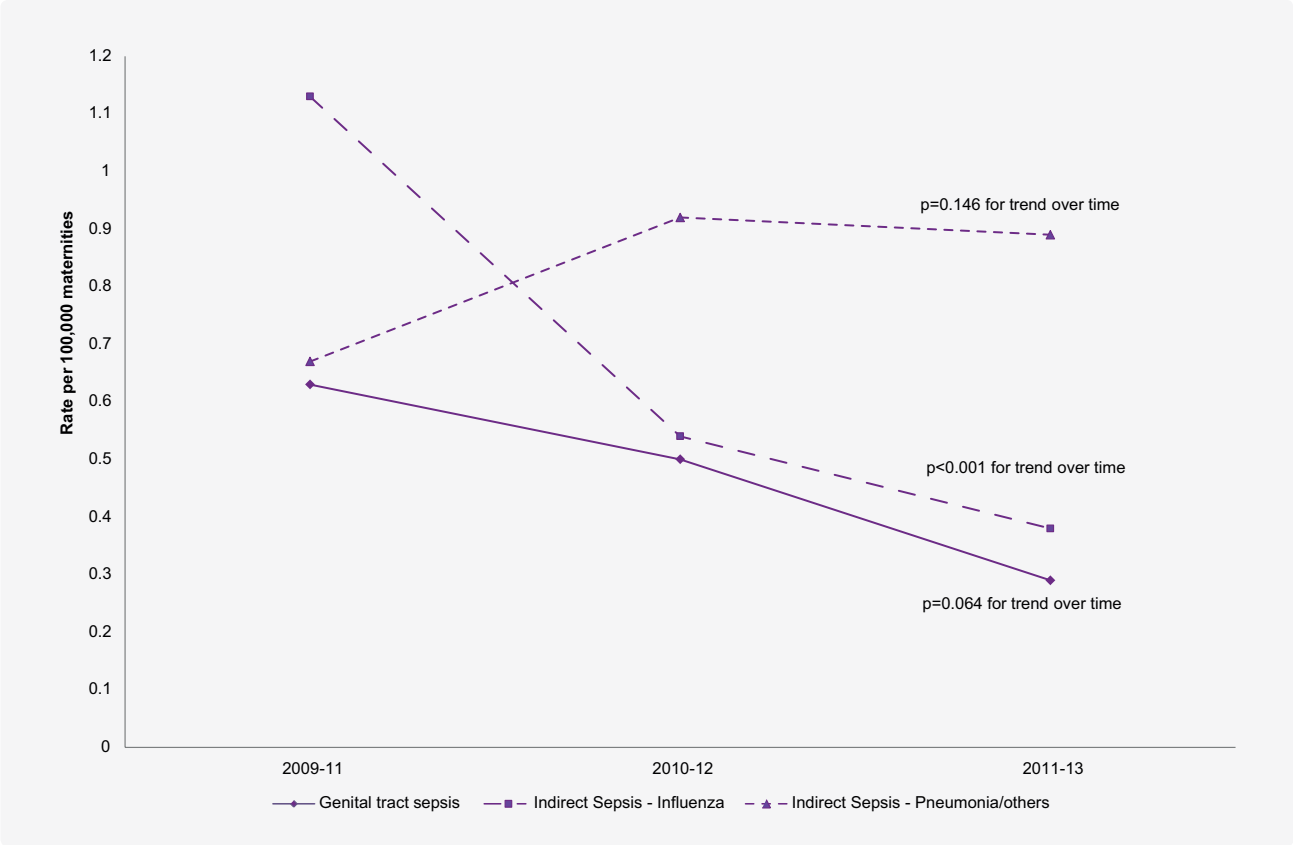
Source: MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency.

Sepsis

There was a decrease in the number of deaths due to genital tract sepsis in 2011-13 (rolling rates shown in Figure 2.4 and table 2.3), consistent with the observed trend in the 2010-12 triennium. Genital tract sepsis has decreased by three-quarters between 2006-8 and 2011-13 (RR=0.26, 95% CI=0.10 to 0.61), although the trend over time was not statistically significant, p=0.08. Maternal deaths due to genital tract sepsis are considered 'direct' deaths; sepsis deaths due to other causes are classified as 'indirect' and were included within the 'other indirect deaths' in the 2014 report. For the purposes of this report, these are now categorised

into two sub-groups 'Influenza' and 'pneumonia/ others'; the rolling maternal death rates for each sub-group is presented in table 2.3 and the trend in rates over time shown in figure 2.4. As discussed above, there has been a significant decrease in the rate of deaths from influenza, but there was no statistically significant change in the rate of indirect death from pneumonia/other infections between 2009 and 2013. Overall, the maternal death rate from sepsis in 2011-13 was 1.56 per 100,000 maternities (95% CI 1.10 to 2.15), not statistically significantly different from the rate in 2006-8 (1.44 per 100,000 maternities, 95% CI 0.99 to 2.02; RR comparing 2006-8 with 2011-13 1.08, 95% CI 0.66 to 1.79, p=0.73).

Figure 2.4: Three-year maternal sepsis death rates by sub-categories of sepsis, 2009-13



Source: MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Direct deaths

Thrombosis and thromboembolism continue to be the leading cause of direct deaths in 2011-13 (Figure 2.3). There was no significant change in the maternal death rate from thrombosis and thromboembolism between 2009 and 2013; p=0.481 for trend over time. An in-depth review of these deaths is presented in chapter 4. There was no significant change in the rates of direct maternal deaths due to other causes; the maternal death rate from pre-eclampsia and eclampsia is once again the lowest ever reported rate (0.25 per 100,000 maternities, 95% CI 0.09-0.55). This represents only one maternal death from hypertensive disorders of pregnancy for every 400,000 women giving birth.

Indirect deaths

As highlighted in the last report, addressing indirect maternal deaths remains a major challenge to the UK health services. There was no statistically significant decrease in the rates of indirect maternal death over the years from 2003-05 to 2011-13 and deaths due to indirect causes still remain the major proportion (68%) of maternal deaths in the UK (Figure 2.3). As in the previous reports, cardiac disease remains the largest single cause of indirect maternal deaths in 2011-13. There was no significant change in the maternal mortality rate from cardiac disease between 2009 and 2013. Among the 49 women who died from a cardiac condition in 2011-13, 12 (25%) were classified as Sudden Adult Death Syndrome (SADS), 10 (20%) had an aortic dissection, 10 (20%) had an acute coronary syndrome, 6 women (12%) died from a

cardiomyopathy and 11 (22%) had other cardiac conditions. A detailed assessment of the care of the women who died from cardiac disease will be included in the 2016 report.

Deaths from indirect causes of sepsis are discussed above. Similar to the 2010-12 triennium, maternal deaths from neurological causes were the third most frequent cause of indirect maternal death. There were 7 deaths from epilepsy in 2011-13 (0.30 per 100,000 maternities, 95% CI = 0.12 to 0.61) and 17 from other neurological causes (0.72 per 100,000 maternities, 95% CI = 0.42 to 1.15). The number of deaths due to epilepsy was higher in 2006-8 compared to 2011-13 (RR=0.48, 95% CI = 0.16 to 1.28), however this difference is not statistically significant (p=0.49). As emphasised in the 2014 report, women with epilepsy require specific care throughout their pregnancy. New guidance from the Royal College of Obstetricians and Gynaecologists will be released next year. Death rates due to other neurological causes are unchanged between 2006-8 and 2011-13 (RR=0.75, 95% CI = 0.37 to 1.47), p=0.17 for trend over time. The rates of indirect death from other causes also remain unchanged. Deaths from psychiatric causes continue to make a significant contribution to late maternal deaths (deaths occurring more than six weeks and up to one year after the end of pregnancy) and are examined in detail in chapter 3. Thus although psychiatric causes represent only the fifth most common individual cause of maternal death during or up to six weeks after the end of pregnancy, almost a quarter of maternal deaths occurring between six weeks and one year after the end of pregnancy are due to psychiatric causes (chapter 7).

International comparison

The international comparison of the UK MMR calculated using routine data collected through death certificates and live birth as denominators for 2012-14 will be updated in the next report. However, a table from the last report is included for reference in this chapter. Table 2.4 shows that the maternal mortality rates for the UK using routinely reported data are much lower than the actual rates. This is because of a high rate of case ascertainment by the UK CEMD due to multiple sources of death identification, and the commitment of maternity staff, Coroners/Procurators Fiscal, pathologists and others to reporting deaths.

Table 2.4: Maternal mortality ratios*, UK: 1985-2011

Triennium	No. of deaths identified through death certificates	Rate	95% CI	Denominator number of live births
1985-87	174	7.67	6.61-8.90	2,268,766
1988-90	171	7.24	6.24-8.42	2,360,309
1991-93	150	6.48	5.52-7.60	2,315,204
1994-96	158	7.19	6.15-8.40	2,197,640
1997-99	128	6.03	5.70-7.17	2,123,614
2000-02	136	6.81	5.76-8.05	1,997,472
2003-05	149	7.05	6.00-8.27	2,114,004
2006-08	155	6.76	5.78-7.92	2,291,493
2009-11	134	5.57	4.67-6.60	2,405,251

Source: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

*Note that this table reports the Maternal Mortality Ratio and not the rate as elsewhere in the report

2.3. The characteristics of women who died 2011-13

The women and babies

Forty-four (21%) of the 214 women who died in 2011-13 were still pregnant at the time of their deaths; more than a third of these women were ≤20 weeks gestation when they died (Table 2.5). Eighteen (8%) women had a pregnancy loss at ≤20 weeks gestation and the remaining 152 women gave birth to a total of 156 infants, 112 (72%) survived, 44 died (33 stillborn and 11 neonatal deaths). The women who died left behind a further 267 children, thus together a total of 379 motherless children remain. The majority of women who gave birth did so in hospital (78%); 17% of women gave birth in an accident and emergency department or an ambulance, and 3% at home (Table 2.6). Ninety-six women were delivered by caesarean section in 2011-13, 38% of these were perimortem caesarean sections. Seventeen babies were born by perimortem caesarean section after 32 weeks of gestation of which 7 survived (6 were stillborn and 4 died in the neonatal period) and 20 babies were born by perimortem caesarean at 32 weeks or less of which 13 died (8 were stillborn and 5 died in the neonatal period). Thus, of the total 37 babies delivered by perimortem caesarean section, 38% survived (38% were stillborn and 24% died in the neonatal period).

Table 2.5: Timing of maternal deaths in relation to pregnancy 2011-13

Time period of deaths in the pregnancy care pathway	Direct (n=69) Frequency (%)	Indirect (n=145) Frequency (%)	Total (n=214) Frequency (%)
Antenatal period			
≤20 weeks	9 (90)	21 (62)	30 (68)
>20 weeks	1 (10)	13 (38)	14 (32)
Postnatal on day of delivery	21 (30)	28 (19)	49 (23)
Postnatal 1-41 days after delivery	38 (55)	83 (57)	121 (56)

Table 2.6: Place of delivery amongst women >20 weeks gestation who died after delivery 2011-13

Place of delivery (for women who gave birth)	Direct (n=51) Frequency (%)	Indirect (n=101) Frequency (%)	Total (n=152) Frequency (%)
Home	2 (4)	3 (3)	5 (3)
Hospital (except A&E)	41 (80)	77 (76)	118 (78)
Emergency Department or ambulance	8 (16)	19 (19)	27 (18)
Not known	0 (0)	2 (2)	2 (1)

Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2011-13 are shown in Table 2.7. As noted in the 2014 report, the rates of maternal mortality varied by age, socioeconomic status and ethnic background of the women, being higher amongst older women, those living in the most deprived areas and amongst women from some ethnic minority groups (Table 2.8). Unlike in previous reports, there was no statistically significant difference between women living in the most deprived areas and those living in the least deprived areas, however, the absolute estimates of the risk difference remain unchanged from previous reports. These characteristics have been shown to be independently associated with increased odds of direct maternal death in the UK after controlling for other known risk factors (Nair, Kurinczuk et al. 2014). Estimated ratios of relative risk (RRR) (Altman and Bland 2003) of maternal death in the different age, socioeconomic and ethnic groups did not show any statistically significant difference between 2012-13 and 2010-11 (Table 2.9), suggesting that there are no significant changes in the inequality gaps across these time-periods.

A quarter of women who died in 2011-13 were born outside the UK; 43% of these women were not UK citizens. Overall 12% of the women who died were not UK citizens. Women who died who were born abroad had arrived in the UK a median of 4 years before they died (range 1 month to 22 years), and 70% were from Asia (mainly India, Pakistan and Bangladesh) and Africa (mainly Nigeria, Somalia,

Ghana and Democratic Republic of Congo), about 18% from Eastern Europe (mostly from Poland) and the remainder from other parts of Europe, Australia and North America. Table 2.10 shows the rates of death amongst women born in selected countries with the highest number of deaths. In contrast to the 2010-12 triennium, in 2011-13 there was no statistically significant difference in maternal death rate between women born in the UK and those born outside the UK. The RR of death among women born outside the UK in 2012-13 was not statistically significantly different from the RR in 2010-11 (RRR = 0.67; 95% CI = 0.38 to 1.18; p=0.16). This may be explained by a difference in the population of non-UK born women giving birth, which now includes more women born in European countries.

Table 2.7: The socio-demographic characteristics of women who died 2011-13

Characteristics	Direct (n=69) Frequency (%)	Indirect (n=145) Frequency (%)	Total (n=214) Frequency (%)
Socio-demographic			
Age			
<20	1 (2)	7 (5)	8 (4)
20 – 24	5 (7)	18 (12)	23 (11)
25 – 29	14 (20)	36 (25)	50 (23)
30 – 34	24 (35)	39 (27)	63 (29)
35 – 39	20 (29)	31 (21)	51 (24)
≥ 40	5 (7)	14 (10)	19 (9)
Parity			
0	26 (38)	45 (31)	71 (33)
1 to 2	30 (44)	75 (52)	105 (49)
≥3	9 (13)	23 (16)	32 (15)
Missing	4 (6)	2 (1)	6 (3)
UK citizen			
Yes	56 (81)	123 (85)	179 (84)
No	9 (13)	16 (11)	25 (12)
Missing	4 (6)	6 (4)	10 (5)
Ethnicity			
White European	42 (61)	107 (74)	149 (70)
Indian	1 (2)	6 (4)	7 (3)
Pakistani	7 (10)	6 (4)	13 (6)
Bangladeshi	1 2)	3 (2)	4 (2)
Other Asian	1 (2)	3 (2)	4 (2)
Black Caribbean	2 (3)	2 (1)	4 (2)
Black African	10 (14)	10 (7)	20 (9)
Others/ Mixed	2 (3)	5 (3)	7 (3)
Missing	3 (4)	3 (2)	6 (3)
Woman's region of birth			
United Kingdom	45 (65)	97 (67)	142 (66)
Eastern Europe	2 (3)	7 (5)	9 (4)
Western Europe	1 (2)	4 (3)	5 (2)
Asia	6 (9)	14 (10)	20 (9)
Africa	9 (13)	9 (6)	18 (8)
Australia and North America	1 (2)	0 (0)	1 (1)
Missing	5 (7)	14 (10)	19 (9)
Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)			
First quintile (Least deprived)	11 (16)	17 (12)	28 (13)
Second quintile	10 (15)	18 (12)	28 (13)
Third quintile	11 (16)	16 (11)	27 (13)
Fourth quintile	14 (20)	35 (24)	49 (23)
Fifth quintile (Most deprived)	18 (26)	46 (32)	64 (30)
Missing	5 (7)	13 (9)	18 (8)
Socioeconomic status (Occupational classification)			
Employed (Either woman or partner)	46 (67)	92 (63)	138 (65)
Unemployed (Both)	6 (9)	22 (15)	28 (13)
Missing	17 (25)	31 (21)	48 (22)
Able to speak/understand English			
Yes	65 (94)	135 (93)	200 (94)
No	3 (4)	8 (6)	11 (5)
Missing	1 (2)	2 (1)	3 (1)
Living arrangements			
With partner	52 (75)	109 (75)	161 (75)
Living alone	2 (3)	10 (7)	12 (6)
With parents/extended family	9 (13)	13 (9)	22 (10)
Homeless/Others	1 (2)	3 (2)	4 (2)
Missing	5 (7)	10 (7)	15 (7)
Domestic abuse (prior to pregnancy/ during pregnancy)			
Yes	3 (4)	11 (8)	14 (7)
No	38 (55)	72 (50)	110 (51)
Missing	28 (41)	62 (43)	90 (42)
Known to social services			
Yes	4 (6)	25 (17)	29 (14)
No	62 (90)	115 (79)	177 (83)
Missing	3 (4)	5 (4)	8 (4)

Table 2.8: Maternal mortality rates amongst different population groups 2011-13

	Total maternities 2011-13	Total deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
Age						
<20	111805	8	7.2	3.1 to 14.1	1.33	0.51 to 3.08
20 – 24	427329	23	5.4	3.4 to 8.1	1 (Ref)	
25 – 29	662206	50	7.6	5.6 to 10.0	1.40	0. 84 to 2.41
30 – 34	701163	63	9.0	6.9 to 11.5	1.67	1.02 to 2.82
35 – 39	374999	51	13.6	10.1 to 17.9	2.53	1.52 to 4.33
≥ 40	95607	19	19.9	12.0 to 31.0	3.69	1.90 to 7.09
IMD Quintiles (England only)						
I (Least deprived/ highest 20%)	291274	22	7.6	4.7 to 11.4	1 (Ref)	-
II	310685	21	6.8	4.2 to 10.3	0.89	0.47 to 1.71
III	361339	21	5.8	3.6 to 8.9	0.77	0.40 to 1.47
IV	442527	45	10.2	7.4 to 13.6	1.35	0.79 to 2.35
V (Most deprived/ lowest 20%)	543159	59	10.9	8.3 to 14.0	1.44	0.87 to 2.46
Ethnic group (England only)						
White (inc. not known)	1582626	123	7.8	6.5 to 9.3	1 (Ref)	-
Indian	63524	7	11.0	4.4 to 22.7	1.42	0.56 to 3.01
Pakistani	81759	13	15.9	8.5 to 27.2	2.05	1.06 to 3.63
Bangladeshi	27297	4	14.7	4.0 to 37.5	1.89	0.51 to 4.95
Other Asian	57295	4	7.0	1.9 to 17.9	0.90	0.24 to 2.36
Caribbean	19690	4	20.3	5.5 to 52.0	2.61	0.70 to 6.86
African	67047	19	28.3	17.1 to 44.3	3.65	2.12 to 5.94
Others/ mixed	103524	6	5.8	2.1 to 12.6	0.75	0.27 to 1.67

Table 2.9: Comparing the relative risk of maternal death among different population groups between 2010-11 and 2012-13

	2010-11		2012-13		Ratio of the relative risks (RRR) (comparing 2012-13 with 2010-11)	95% CI	P-value
	Relative risk (RR)	95% CI	Relative risk (RR)	95% CI			
Age							
<20	1.25	0.51 to 2.77	0.91	0.17 to 3.30	0.73	0.13 to 4.01	0.72
20 – 24	1 (Ref)	-	1 (Ref)	-	-	-	-
25 – 29	1.11	0.66 to 1.91	1.6	0.82 to 3.32	1.44	0.60 to 3.47	0.41
30 – 34	1.28	0.77 to 2.16	1.72	0.90 to 3.52	1.34	0.57 to 3.16	0.50
35 – 39	1.47	0.84 to 2.59	2.93	1.51 to 6.06	1.99	0.82 to 4.87	0.13
≥ 40	3.88	2.04 to 7.28	3.36	1.32 to 8.29	0.86	0.28 to 2.64	0.80
IMD Quintiles (England only)							
I (Least deprived/ highest 20%)	1 (Ref)	-	1 (Ref)	-	-	-	-
II	1.16	0.58 to 2.33	0.7	0.30 to 1.58	0.6	0.20 to 1.78	0.36
III	1.09	0.56 to 2.18	0.45	0.18 to 1.09	0.41	0.13 to 1.28	0.12
IV	1.4	0.76 to 2.65	1.11	0.58 to 2.20	0.79	0.32 to 1.98	0.62
V (Most deprived/ lowest 20%)	1.55	0.88 to 2.87	1.1	0.59 to 2.15	0.71	0.30 to 1.70	0.44
Ethnic group (England only)							
White (inc. not known)	1 (Ref)	-	1 (Ref)	-	-	-	-
Indian	2.79	1.35 to 5.22	0.69	0.08 to 2.59	0.25	0.04 to 1.60	0.14
Pakistani	1.59	0.67 to 3.26	2.12	0.88 to 4.40	1.33	0.43 to 4.12	0.62
Bangladeshi	1.19	0.14 to 4.42	1.58	0.19 to 5.93	1.33	0.12 to 15.19	0.82
Other Asian	1.16	0.31 to 3.06	0.75	0.09 to 2.82	0.65	0.08 to 5.11	0.68
Caribbean	0.8	0.02 to 4.55	4.41	1.17 to 11.79	5.51	0.29 to 105.2	0.26
African	3.55	1.95 to 6.06	3	1.32 to 6.01	0.85	0.33 to 2.18	0.73
Others/ mixed	1.11	0.44 to 2.38	1.03	0.33 to 2.53	0.93	0.25 to 3.48	0.91

Table 2.10: Maternal mortality rates according to mother's country of birth (selected countries)

Woman's country of birth	Maternities 2011-13	Total Deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
UK	1804761	142	7.9	6.6 to 9.3	1 (Ref)	-
Outside UK	568452	53	9.3	7.0 to 12.2	1.18	0.85 to 1.64
Specific countries						
Bangladesh	24493	3	12.3	2.5 to 35.8	1.56	0.32 to 4.64
India	43685	5	11.5	3.7 to 26.7	1.45	0.47 to 3.48
Pakistan	56448	8	14.2	6.1 to 27.9	1.80	0.76 to 3.65
Democratic Republic of Congo	1723	2	116.1	14.1 to 418.7	14.75	1.77 to 54.28
Nigeria	22499	5	22.2	7.2 to 51.9	2.82	0.90 to 6.75
Somalia	15808	3	19.0	3.9 to 55.5	2.41	0.49 to 7.19
Poland	64534	5	7.8	2.5 to 18.1	0.98	0.31 to 2.35

Medical and pregnancy-related characteristics

A study using data from the 2014 report showed that medical co-morbidities are significantly associated with maternal death from direct pregnancy causes (Nair, Kurinczuk et al. 2015). Two-thirds (66%) of the women who died in 2011-13 were known to have medical co-morbidities (Table 2.11), 13% were known to have pre-existing mental health problems. Thirty percent of women who died in 2011-13 were obese and 22% were overweight (Table 2.11). Obesity was shown in the previously noted analysis to be independently associated with higher odds of dying from specific pregnancy complications (Nair, Kurinczuk et al. 2015).

The pregnancy-related characteristics of the women who died in 2011-13 are shown in Table 2.12.

Table 2.11: Selected medical conditions and characteristics identified amongst women who died 2011-13

Medical condition/characteristic	Direct (n=69) Frequency (%)	Indirect (n=145) Frequency (%)	Total (n=214) Frequency (%)
Body mass index (BMI)			
<18	0 (0)	3 (2)	3 (1)
18 – 24	24 (35)	57 (39)	81 (38)
25 – 29	16 (23)	30 (21)	46 (22)
≥ 30	22 (32)	42 (29)	64 (30)
Missing	7 (10)	13 (9)	20 (9)
Mental health problems or psychiatric disorders			
Yes	6 (9)	22 (15)	28 (13)
No	61 (88)	119 (82)	180 (84)
Missing	2 (3)	4 (3)	6 (3)
Any pre-existing medical problem (excluding obesity)			
Yes	43 (62)	98 (68)	141 (66)
No	24 (35)	43 (30)	67 (31)
Missing	2 (3)	4 (3)	6 (3)

Table 2.12: Pregnancy-related characteristics of the women who died 2011-13

Characteristics	Direct (n=69) Frequency (%)	Indirect (n=145) Frequency (%)	Total (n=214) Frequency (%)
Pregnancy known to be as a result of assisted reproductive techniques			
Yes	3 (4)	1 (1)	4 (2)
No	63 (91)	137 (94)	200 (93)
Missing	3 (4)	7 (5)	10 (5)
Multiple pregnancy			
Yes	2 (3)	3 (2)	5 (2)
No	64 (93)	138 (95)	202 (94)
Missing	3 (4)	4 (3)	7 (3)
Previous caesarean section			
Yes	16 (23)	30 (21)	46 (21)
No	49 (71)	113 (78)	162 (76)
Missing	4 (6)	2 (1)	6 (3)
Previous caesarean numbers (among women who had a previous caesarean section)			
1	12 (75)	25 (83)	37 (80)
≥2	4 (25)	5 (17)	9 (20)

Other characteristics of women who died

Substance misuse and inadequate utilisation of antenatal care services have been shown to be associated with increased odds of maternal death from specific causes in the UK (Nair, Kurinczuk et al. 2015). The pattern of prevalence of these risk factors among women who died in 2011-13 did not differ from that noted in the 2014 report (Table 2.13). As highlighted in the last report, use of antenatal care remains an issue (whether due to lack of access or other factors) amongst women who died in this triennium. Only a third of the women who received antenatal care, received the recommended level of care according to NICE antenatal care guidelines (booking at 10 weeks or less and no routine antenatal visits missed) (National Institute for Health and Care Excellence 2008).

Table 2.13: Other characteristics of women who died 2011-13

Characteristics	Direct (n=69) Frequency (%)	Indirect (n=145) Frequency (%)	Total (n=214) Frequency (%)
Smoking			
Smoker	11 (16)	38 (26)	49 (23)
Non-smoker	46 (67)	88 (61)	134 (63)
Missing	12 (17)	19 (13)	31 (15)
Substance user			
Yes	1 (2)	13 (9)	14 (7)
No	65 (94)	130 (90)	195 (91)
Missing	3 (4)	2 (1)	5 (2)
Received any antenatal care*			
Yes	58 (84)	134 (92)	192 (90)
No	9 (13)	11 (8)	20 (9)
Missing	2 (3)	0 (0)	2 (1)
Gestational age at booking (among women who received any antenatal care)			
≤10	23 (40)	59 (44)	82 (43)
11 – 12	24 (41)	36 (27)	60 (31)
>12	9 (16)	29 (22)	38 (20)
Missing	2 (3)	10 (7)	12 (6)
Received recommended antenatal care† (among women who received any antenatal care)			
Yes	20 (34)	44 (33)	64 (33)
No	34 (59)	77 (58)	111 (58)
Missing	4 (7)	13 (10)	17 (9)
Received a minimum level of antenatal care† (among women who received any antenatal care)			
Yes	44 (76)	84 (63)	128 (67)
No	9 (16)	33 (25)	42 (22)
Missing	5 (7)	17 (13)	22 (11)

*Includes 5 women who died in early pregnancy. †NICE recommended antenatal care: booked at 10 weeks or less and no antenatal visits missed. Minimum level of care: booked at less than 13 weeks and 3 or fewer antenatal visits missed.

Quality of care received

This section includes information from women who died between 2009 and 2013 and are included in the confidential enquiry chapters of this report (including late deaths and women from the Republic of Ireland). Table 2.14 shows the classification of care as agreed by the assessors for 248 women whose case notes were available with sufficient information for an in-depth review. Among women who died during or within 42 days of the end of pregnancy, 41% were assessed to have received good care. Among the women who died between six weeks and one year after the end of pregnancy, for whom case notes were available, 43 (31%) women were considered to have received good care after detailed assessment.

Table 2.14: Classification of care received by women who died and for whom case notes were available for an in-depth review and are included in the confidential enquiry chapters (2009-13)

Classification of care received	Deaths within 42 days (n=108)* Number (%)	Late deathsł (n=140)* Number (%)
Good care	44 (41)	43 (31)
Improvements to care which would have made no difference to outcome	23 (21)	36 (26)
Improvements to care which may have made a difference to outcome	41 (38)	61 (43)

ł Deaths between 42 days and one year of end of pregnancy irrespective of cause of death; *includes women whose case notes were available with sufficient information for an in-depth review

Local clinicians reports

It was noted in the 2014 report that local clinicians' reports had only been received for 18% of those requested for the confidential enquiry. It is encouraging that for women who died in 2013, this figure has increased overall to 60%. However, only with 100% can MBRRACE-UK assessors fully take account of any local factors impacting on care. Figures for different specialty groups are listed in table 2.15.

Table 2.15: Percentages of local clinicians' reports received for women who died in 2013

Specialty group	Percentage of reports requested that were received
Obstetricians	63
Anaesthetists	57
Midwives	58
Critical Care Clinicians	65
Emergency Medicine Specialists	41
GPs	69
Physicians	35
Psychiatrists	67
Total	**60**

3. Lessons on maternal mental health

Roch Cantwell, Marian Knight, Margaret Oates and Judy Shakespeare on behalf of the MBRRACE-UK mental health chapter writing group

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3.1. Key messages

Good communication between primary care, mental health and maternity services is critical to good quality care for women with mental ill health, in particular:

- At booking there should be a routine enquiry about a current or past history of mental health problems, which should cover the full range of mental health issues and not just depression.
- Maternity services should ensure that the GP is made aware of a woman's pregnancy and enquire of the GP about the woman's past mental health history.

The following are 'red flag' signs for severe maternal illness and require urgent senior psychiatric assessment:

- Recent significant change in mental state or emergence of new symptoms
- New thoughts or acts of violent self-harm
- New and persistent expressions of incompetency as a mother or estrangement from the infant

Admission to a mother and baby unit should always be considered where a woman has any of the following:

- rapidly changing mental state,
- suicidal ideation (particularly of a violent nature),
- pervasive guilt or hopelessness,
- significant estrangement from the infant,
- beliefs of inadequacy as a mother,
- evidence of psychosis.

Perinatal mental health clinical networks should be established to develop local services and clear pathways of care to prevent care being fragmented and uncoordinated. Networks should always include specialist addictions services.

Liaison, crisis and home treatment teams require additional support and education in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women.

Partners and other family members may require explanation and education regarding maternal mental illness and its accompanying risks.

Mental Health Services should publicise the findings of this report and its procedures widely among mental health staff in order to highlight the messages directly relevant to improving care for pregnant and postpartum women with mental health problems.

3.2. Background

Women are at higher risk of experiencing new-onset severe mental illness in the early postpartum period than at any other time in their lives (Kendell, Chalmers et al. 1987). A range of pre-existing mental disorders may return or worsen in the postnatal period and there is a clearly established link between bipolar affective disorder and vulnerability to early postpartum psychosis, which is likely to represent an underlying biological predisposition (Jones, Hamshere et al. 2007). Pregnancy does not protect against mental illness, and the particular personal and social demands of pregnancy and caring for a new baby may place additional risks on women with pre-existing disorders.

Mental disorder, and deaths from suicide in particular, have emerged as one of the leading causes of maternal death in earlier confidential enquiries (Oates and Cantwell 2011). Key previous findings include:

- the high risk of severe mental disorder in the early postpartum
- a failure to recognise the suddenness of onset
- seriousness of illness and rapidity of deterioration
- poor information sharing between primary care, maternity and mental health services,
- a lack of detailed enquiry and naïve management for women with substance misuse
- women who died of underlying physical illness had their symptoms downplayed or diagnosis delayed because of misattribution to mental disorder.

Specialist perinatal mental health services remain poorly provided in many areas of the UK and Ireland (Everyone's Business Campaign 2014, NSPCC Scotland 2015). The lack of access to dedicated services for pregnant and postnatal women has been highlighted in previous enquiries. However, screening for the risk, or presence, of mental disorder is the responsibility of all health professionals in contact with pregnant and postnatal women.

3.3. Summary of the key findings 2009-13

Overall, in this 5-year period, 101 women died by suicide and 58 women died as a consequence of substance misuse either during pregnancy or up to one year after the end of pregnancy. A further two women died from other mental-health related causes, thus a total of 161 women died from mental health-related causes during or up to one year after the end of pregnancy. This represents a rate of 3.7 deaths from mental health-related causes during or up to one year after the end of pregnancy per 100,000 maternities in the UK and Ireland for 2009-13 (95% CI 3.2-4.4), and a rate of 2.3 deaths by suicide during or up to one year after the end of pregnancy per 100,000 maternities (95% CI 1.9-2.8). The deaths of all 101 women who died by suicide were reviewed in detail, although limited information was available about 8 of the women who died more than six months after the end of pregnancy. The deaths of 29 women who died in relation to substance misuse and for whom adequate records were available was reviewed in detail.

In addition, messages from the care of a further five women, whose deaths were classified in other chapters (in both this and the 2014 report) are included here.

The characteristics of women who died are shown in Tables 3.1 and 3.2. For the women who died by suicide, the median age at death was 29 years. The majority were white, UK citizens. Most had one or two previous deliveries. Almost a quarter of the women were known to social services. Seventeen of the women (17%) who died by suicide are known to have a history of domestic abuse, 32 women (32%) did not have a history of domestic abuse. For 52 women (51%) who died by suicide, it is unknown whether they had a history of domestic abuse. It is unclear whether this is because domestic abuse was not present but the absence of abuse was undocumented, or that a history of domestic abuse was not elicited, i.e. that the women had never been asked. This is discussed further in chapter 6. With respect to antenatal care, at least two thirds of women who died by suicide received some care but only a quarter of them received the recommended level of care. Importantly, a quarter of the women who died by suicide booked late for antenatal care (greater than 12 weeks' gestation).

For the substance misuse group the median age at death was 30 years. When compared to those women who died by suicide, this group were more likely to be from deprived backgrounds and less likely to be employed. They were more likely to have booked late for antenatal care (50% of women booked late of those with data available) and less likely to receive a minimum level of antenatal care.

Table 3.1: The socio-demographic characteristics of women who died as a result of psychiatric causes 2009-13 in the UK and Ireland

Characteristics	Suicide (n=101*) Frequency (%)	Substance misuse (n=58) Frequency (%)	Total (n=161**) Frequency (%)
Socio-demographic			
Age			
<20	8 (8)	2 (3)	10 (6)
20 – 24	14 (14)	8 (14)	22 (14)
25 – 29	30 (30)	13 (22)	44 (27)
30 – 34	19 (19)	19 (33)	39 (24)
35 – 39	22 (22)	12 (21)	34 (21)
≥ 40	7 (7)	4 (7)	11 (7)
Missing	1 (1)	0 (0)	1 (1)
Parity			
Nulliparous	30 (30)	9 (16)	41 (25)
Multiparous	54 (53)	20 (34)	74 (46)
Missing	17 (17)	29 (50)	46 (29)
UK citizen			
Yes	74 (73)	25 (43)	101 (63)
No	15 (15)	4 (7)	19 (12)
Missing	12 (12)	29 (50)	41 (25)
Ethnicity			
White	75 (74)	26 (45)	102 (63)
Black or other minority ethnic group	18 (18)	3 (5)	21 (13)
Missing	8 (8)	29 (50)	38 (24)
Woman's region of birth			
United Kingdom or Ireland	73 (72)	26 (45)	101 (63)
Other European countries	6 (6)	2 (3)	8 (5)
Asia/ Africa	9 (9)	0 (0)	9 (5)
Missing	13 (13)	30 (52)	43 (27)
Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)			
First quintile (Least deprived)	10 (10)	3 (5)	13 (8)
Second quintile	13 (13)	3 (5)	16 (10)
Third quintile	19 (19)	5 (8)	24 (15)
Fourth quintile	14 (14)	11 (18)	25 (16)
Fifth quintile (Most deprived)	28 (28)	16 (26)	44 (27)
Missing	16 (16)	23 (38)	39 (24)
Socioeconomic status (Occupational classification)			
Employed (Either woman or partner)	58 (57)	11 (19)	71 (44)
Unemployed (Both)	18 (18)	12 (21)	30 (19)
Missing	25 (25)	35 (60)	60 (37)
Able to speak/understand English			
Yes	87 (86)	29 (50)	118 (73)
No	5 (5)	0 (0.00)	5 (3)
Missing	9 (9)	29 (50)	38 (24)
Living arrangements			
With partner	58 (57)	14 (24)	74 (46)
Living alone	16 (16)	5 (9)	21 (13)
With parents/extended family	7 (7)	2 (3)	9 (5)
Social care/ Homeless/No fixed abode/others	5 (5)	6 (10)	11 (7)
Missing	15 (15)	31 (53)	46 (29)
Domestic abuse (prior to pregnancy/ during pregnancy)			
Yes	17 (17)	9 (15)	26 (16)
No	32 (32)	8 (14)	40 (25)
Missing	52 (51)	41 (71)	95 (59)
Known to social services			
Yes	24 (24)	20 (34)	44 (27)
No	64 (63)	7 (12)	73 (45)
Missing	13 (13)	31 (53)	44 (27)

Note: Missing group includes 37 women (29 Substance misuse and 8 Suicide) identified from the ONS and NRS for whom case notes were not available.

*The suicide group includes 14 women who also had drug and alcohol related problems; **Total includes two women who died from other mental-health related causes

Table 3.2: Other characteristics of women who died as a result of psychiatric causes 2009-13 in the UK and Ireland

Characteristics	Suicide (n=101*) Frequency (%)	Substance misuse (n=58) Frequency (%)	Total (n=161**) Frequency (%)
Body mass index (BMI)			
<18	5 (5)	1 (2)	6 (4)
18 – 24	45 (44)	13 (22)	59 (37)
25 – 29	16 (16)	7 (12)	24 (15)
≥ 30	9 (9)	1 (2)	10 (6)
Missing	26 (26)	36 (62)	62 (38)
Smoking			
Smoker	36 (36)	21 (36)	57 (35)
Non-smoker	47 (46)	5 (9)	54 (34)
Missing	18 (18)	32 (55)	50 (31)
Received any antenatal care			
Yes	82 (81)	27 (47)	111 (69)
No	9 (9)	2 (3)	11 (7)
Missing	10 (10)	29 (50)	39 (24)
Gestational age at booking (among women who received any antenatal care)			
≤10	27 (33)	7 (26)	34 (31)
11 – 12	29 (35)	1 (4)	31 (28)
>12	24 (29)	16 (59)	40 (36)
Missing	2 (2)	3 (11)	6 (5)
Received recommended antenatal care (among women who received any antenatal care)			
Yes	19 (23)	5 (19)	24 (22)
No	58 (71)	19 (70)	78 (70)
Missing	5 (6)	3 (11)	9 (8)
Received a minimum level of antenatal care (among women who received any antenatal care)			
Yes	49 (60)	7 (26)	57 (51)
No	28 (34)	17 (63)	45 (41)
Missing	5 (6)	3 (11)	9 (8)

Note: Missing group includes 37 women (29 Substance misuse and 8 Suicide) identified from the ONS and NRS for whom case notes were not available.

*The suicide group includes 14 women who also had drug and alcohol related problems; **Total includes two women who died from other mental-health related causes

3.4. Overview of care and lessons to be learned

Women who died by suicide

Method, timing and diagnostic category

Violent death

As in previous enquiries, one of the starkest findings is the mode of suicide. Eighty-three women died by violent means, 82% of the total suicide deaths (Table 3.3), a rate of 1.9 violent suicides per 100,000 maternities (95% CI 1.5-2.4 per 100,000). This compares with proportions of suicides by violent means of 64% and 62% respectively for women in the general and mental health populations (personal communication, National Confidential Enquiry into Suicide and Homicide). From this information we can infer that the women who died by suicide were, in the main, clear about the intended outcome of their act. The most common method of violent death was hanging (n=46), followed by falling from a height (n=15) and being hit by a train (n=7). Other methods used included drowning (n=4), self-strangulation/asphyxiation (n=2), stabbing (n=2), intentional RTA (n=2) and other causes (n=5).

Violent methods formed the greater proportion of all suicides in all time periods in pregnancy and the postnatal period (Table 3.4 and Figure 3.1).

Table 3.3 Mode of suicide amongst women who died by suicide (n=101), UK and Ireland 2009-13

	Violent n (%)	Non-violent n (%)	TOTAL* n
Associated with substance misuse	7 (50)	6 (43)	14*
Not associated with substance misuse	76 (87)	11 (13)	87
Total	**83 (82)**	**17 (17)**	**101**

*Includes one woman for whom the method is unknown

Figure 3.1: Timing of violent suicide deaths in relation to pregnancy 2009-13

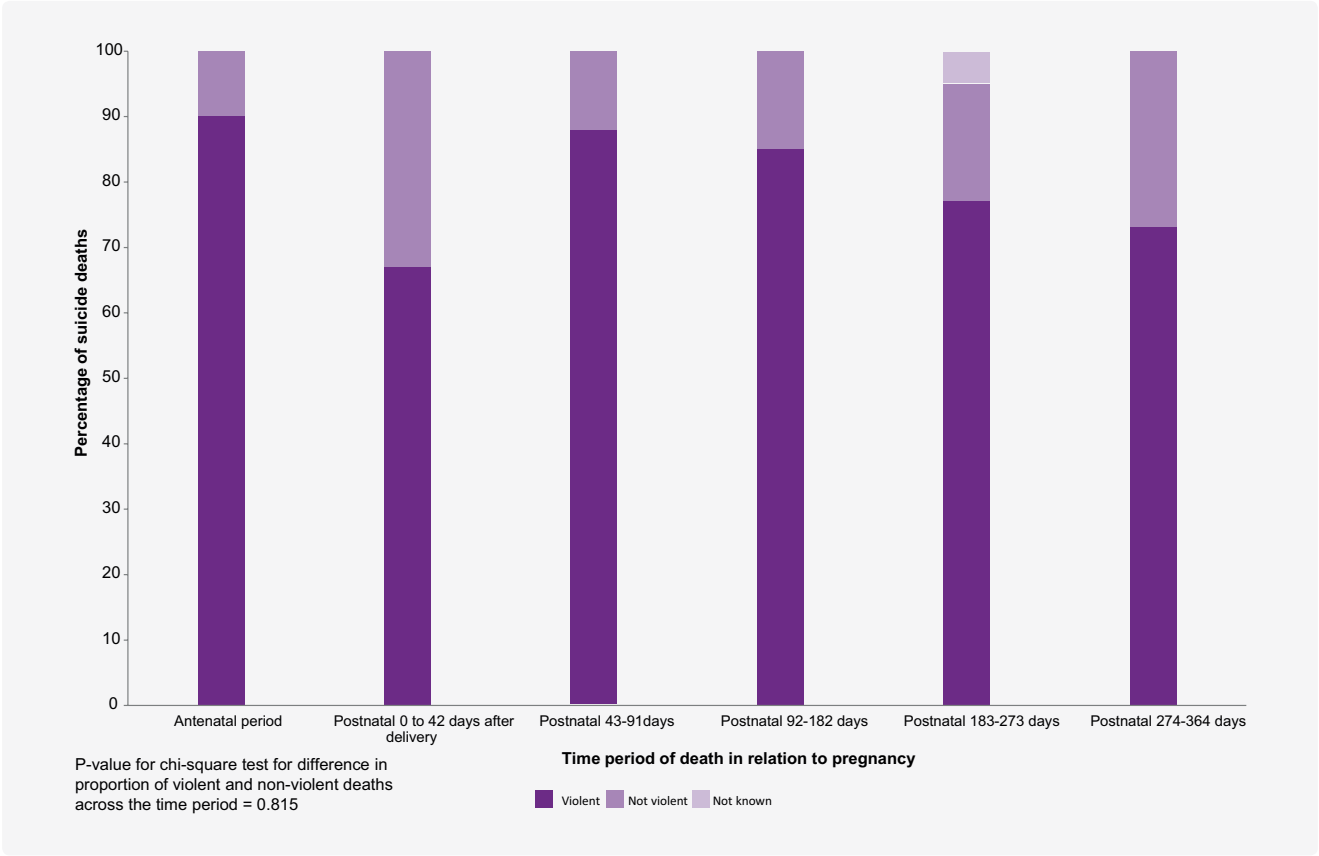

Table 3.4: Timing of the deaths of women who died from mental-health related causes in relation to pregnancy, UK and Ireland 2009-13

Time period of deaths in the pregnancy care pathway	Suicide (n=101*) Frequency (%)	Substance misuse (n=58) Frequency (%)	Total (n=161**) Frequency (%)
Antenatal period	12 (12)	5 (9)	17 (11)
Postnatal 0 to 6 weeks after delivery	9 (9)	6 (10)	16 (10)
Postnatal more than 6 weeks but less than 3 months after delivery	17 (17)	10 (17)	28 (17)
Postnatal 3 months or more but less than 6 months after delivery	26 (26)	11 (19)	37 (23)
Postnatal 6 months or more but less than 9 months after delivery	22 (22)	14 (24)	36 (22)
Postnatal 9 months or more but less than 12 months after delivery	15 (15)	12 (21)	27 (17)

*The suicide group includes 14 women who also had drug and alcohol related problems; **Total includes two women who died from other mental-health related causes

Violent suicide is an indicator of clear intent and underlying significant mental disorder. Any expression of suicidal thoughts in pregnancy or the postpartum period should be taken seriously and mental health services should have a low threshold for initial and ongoing assessment.

A married woman of Asian background had mounting anxiety about the welfare of her pregnancy in the third trimester, against a background of previous pregnancy loss. While still an inpatient on the postnatal wards she expressed concern that something dreadful had gone wrong with the delivery. After returning home, she described ongoing fears that she couldn't cope with her baby. Visiting maternity staff did their best to arrange obstetric review. Her family became increasingly concerned about her mental health and the health visitor arranged to review this. However, she died by violent means within two weeks of the birth. Despite well-intentioned care, her rapidly deteriorating mental state was not fully recognised and mental health services were not involved.

Timing

All time periods after childbirth pose a greater risk for suicide, when compared with the nine-month antenatal period (Table 3.4). For the majority of women, however, the onset of their illness occurred weeks or months before their eventual suicide. The early postpartum onset of severe maternal mental illness has been noted previously, and its suddenness and rapidity of progression was observed once again amongst the women assessed here.

Diagnosis

Where there was sufficient information to diagnose the mental illness women had at the time of their deaths (for 78 women), the most common diagnosis was recurrent depressive disorder (n=45), accounting for almost half of all women. The next most common category was single depressive episode (n=14). Psychotic symptoms were present in 22 women.

Where a diagnosis could be ascertained, over half of the women who died by suicide (n=57) had a diagnosis of a recurrent mental health disorder. A history of mental illness is an indicator of early postpartum high risk, and this risk is highest for bipolar affective disorder and schizophrenia (Munk-Olsen, Laursen et al. 2009). Two women had a prior diagnosis of bipolar disorder and two had schizophrenia. Three out of four of these women had psychiatric care in pregnancy and two had inpatient psychiatric care. However none were referred to specialised perinatal mental health services.

Services need to be aware that the risk of suicide may be present for patients with other disorders as well, particularly where a past diagnosis was one of psychotic or severe non-psychotic disorder. The most common prior diagnosis for women who died by suicide was recurrent depressive disorder. All but one of these women had a diagnosis of moderate or severe disorder. One quarter had psychotic symptoms. It is very important that services remember that all past history should be communicated in early pregnancy whether or not it was associated with the perinatal period.

Fourteen women, who died by suicide, also had a substance misuse diagnosis. In this group, the most frequent additional diagnosis was recurrent depressive disorder (n=5), followed by emotionally unstable personality disorder (n=4) and adjustment disorder (n=2). Three women had other diagnoses.

Women who are at risk of suicide are likely to have an underlying significant mental illness and to have had a previous history of mental health problems. Where there is a past history, this should be communicated to maternity services and routinely enquired for at booking.

(Scottish Intercollegiate Guidelines Network 2012, National Institute for Health and Care Excellence 2014a)

Comorbid substance misuse

As noted above, 14 women who died by suicide had comorbid substance misuse. The reviewers require clear evidence of intentional drugs overdose to include a woman in this group. For that reason, the number of women who were substance misusers, and who died by suicide, may be greater than that identified for the report. Of the 14 women, 7 died by violent means, 6 through overdose, and in one woman the mode of death was not identified. Polysubstance misuse predominated and it was unusual for a woman to be misusing alcohol alone. These women were characterised by complex patterns of substance misuse, mental health, social and medical problems and child protection proceedings were often underway or completed at the time of death. They often engaged poorly with maternity and mental health care. For some women, considerable efforts were made to sustain contact, but not all women were engaged with specialist addiction services despite their high levels of substance use.

Pregnant and postpartum women who are substance misusers often have complex social and mental health issues and these women need access to assertive outreach care from specialist addictions and mental health services.

Death of the baby

In a very small number of women, the baby, or older children, died with the mother (extended suicide). These women all had a diagnosis of depressive disorder. There had been no expressions of thoughts of harm toward the baby. In the majority, there were child safeguarding issues which may have acted as a precipitant for the act.

Extended suicide remains a very rare occurrence but sensitive enquiry should always be made regarding any thoughts of harm toward the infant or older children.

Communication issues

Communication between primary care, maternity and mental health services

In at least 16 of the 57 women with a prior history of mental health problems, who died by suicide, there was evidence that significant aspects

of the woman's past psychiatric history were not communicated between primary care and maternity services. In several instances, maternity services had not been informed of a woman's past psychiatric history and in some circumstances the GP was unaware that the women had booked for maternity care.

A married professional woman died by violent means a few months after the birth of her child. She had developed a significant depressive disorder, including suicidal ideation, after the loss of her previous pregnancy. This was managed in primary care but the history was not passed on to maternity services at booking in the next pregnancy. After her baby was born she did not attend her postnatal review but the health visitor was not made aware. She died in close proximity to the anniversary of her previous pregnancy loss.

This woman's death illustrates the importance of highlighting any past psychiatric history at booking and communicating any evidence of disengagement with care particularly at a vulnerable time.

It is the responsibility of both the midwife and the GP to ensure that significant medical history is shared. This may be facilitated by allowing midwives direct computer system access within the GP practices where they care for women. GPs should send a summary of a woman's medical history in response to a notification that she has booked for maternity care; the midwife needs to ensure that this booking notification is sent.

There is a clear duty on all health professionals to pass on relevant information which may affect the care a woman receives during pregnancy or alter her outcomes.

GPs should inform maternity services of any past psychiatric history and maternity services should ensure that the GP is made aware of a woman's pregnancy and enquire of the GP about past psychiatric history.

If the woman is already known to mental health services, they should be made aware that she is pregnant, and they have the same duty of care to the woman to inform maternity services of any risk she faces.

(Royal College of Obstetricians and Gynaecologists 2011, Scottish Intercollegiate Guidelines Network 2012, National Institute for Health and Care Excellence 2014a)

Communication between private and NHS carers

In three women, there was evidence of difficulties in communication between private and NHS services. NHS carers were either unaware, or unable to access details, of private care accessed by the woman. Information on assessment and risk was not passed on and care was fragmented.

A woman with a diagnosis of bipolar disorder died following an overdose a short time after termination of pregnancy. Although she had been engaged with mental health services, they were not informed of the pregnancy and she was discharged in early pregnancy because of non-attendance. The private clinic did not inform the GP about the termination or of her significant depressive symptoms which were noted a week after the procedure, although mental health services were asked to review her. No one appeared to appreciate the high risk she faced given her bipolar diagnosis.

Good communication and, particularly, effective communication of risk, is the responsibility of all health professionals, irrespective of the setting in which they work.

Assessment issues

Booking assessments

In at least 11 of the 101 women who died by suicide (11%), there was either an inadequate or no enquiry made at booking about mental health history or current mental ill health. Questions about mental health, if present, varied enormously between different services. In some instances, even where appropriate questions formed part of the booking proforma, they remained blank.

All booking questionnaires must include questions to identify (i) women at high risk of early postpartum serious mental illness and (ii) women with current mental health problems. Guidance on what questions should be asked are provided in SIGN Guideline 127: Management of perinatal mood disorders (2012) and RCOG Good Practice Statement No. 14: Management of Women with Mental Health Issues during Pregnancy and the Postnatal Period (2009).

(Royal College of Obstetricians and Gynaecologists 2011, Scottish Intercollegiate Guidelines Network 2012, National Institute for Health and Care Excellence 2014a)

Under-recognition of symptom seriousness or pattern of escalating mental health disturbance

Some women's symptoms were identified as 'anxiety' at first presentation. While this may have been their only initial symptom, their presentation in the early postpartum period with a newly emergent significant change in mental state should have alerted staff caring for them to the presence of more severe illness (Box 3.1).

A related finding is the lack of recognition of an escalating symptom pattern with the assessment of each presentation occurring 'in the moment', without reference to previous assessments, often made only hours or days earlier. It is important to look at symptom patterns over time to get an accurate picture of illness progression.

A further example of downgrading of symptoms, newly described in this enquiry, is the use of terms such as 'impulsive' and 'no planning' when documenting suicide risk assessments. In a number of instances, this appeared a superficial judgement, relying solely on the patient's reported answers, despite evidence of escalating patterns of disturbed behaviour, seriousness of the act, sudden change from usual mental state, and underlying mental illness.

A woman died by violent means several months after the birth of her second child. She had a history of mental health problems including clear depressive disorder prior to her first pregnancy, associated with self-harm. She had a return of depression in that postnatal period. None of this information was passed on to maternity services. Her health visitor found her to be depressed three weeks after delivery and she expressed suicidal ideation to her GP. It was felt that her problems were stress-related but she was commenced on antidepressants. Subsequently, a relative contacted her GP to express significant concerns about her mental state. On review she described ongoing thoughts of self-harm. She was referred for psychiatric assessment but did not attend. A few weeks later she was seen at the Emergency Department following an overdose. The mental health assessment describes a number of depressive symptoms but concluded that the overdose was impulsive. She was discharged to GP care. Six weeks later she presented to out of hours primary care with self-injury. She was described as having multiple suicidal ideas but no fixed plans, and her self-harm as 'impulsive'. Five days later a mental health crisis team concluded that there was no requirement for follow-up. She died by suicide four weeks later.

Pregnancy, and the postnatal period, is a time of greater risk. Clinicians should be alert to sudden changes in mental state and not ascribe symptoms to 'anxiety' without positive evidence. At the very least, new symptoms should be followed up within a short time frame. Terms such as 'impulsive' and 'no planning' should be used with great caution, and are inappropriate if the evidence points to recent similar behaviours and a recently changed mental state.

Assessments should always include a review of previous history and always take into account the findings of recent presentations and escalating patterns of symptoms, their severity and any associated abnormal behaviour.

Precursor thoughts or acts of violent self-harm

A new finding in this enquiry is the lack of recognition or downplaying of thoughts or acts of violent self-harm as a precursor of completed suicide. This was evident in 19 women, almost one in five of the women who died by suicide. Almost half of these women had self-harmed in a violent manner shortly before their deaths but again each incident was assessed 'in the moment'.

A woman died by violent means a few months after the birth of her third child. She had a history of depression in a previous postnatal period and developed depressed mood again soon after her baby was born. Within a fortnight of giving birth she was prescribed antidepressants. A few weeks after delivery she was found on a bridge with a rope. She was judged in the Emergency Department not to have ongoing suicidal intent and followed up by crisis services. A review of her death a month later commented that her subsequent suicide was 'completely unexpected'.

This woman showed clear evidence of violent suicidal intent and yet this was not taken seriously.

New expressions or acts of violent self-harm are 'red flag' symptoms and should always be regarded seriously

Estrangement from the infant

Seven women who died by suicide voiced strong beliefs that they had no relationship with their baby or had arranged for the baby to be cared for by others. This is a new finding and represents a further 'red flag' behaviour. Expressions of incompetence in caring for, or avoidance of, the infant is often an indication of overvalued or frankly psychotic thinking and, particularly where this is a departure from usual mental state, is a clear indicator of risk to the woman.

Box 3.1 'Red Flag' presentations which should prompt urgent senior psychiatric assessment

- Recent significant change in mental state or emergence of new symptoms
- New thoughts or acts of violent self-harm
- New and persistent expressions of incompetency as a mother or estrangement from the infant

A woman died by violent means a few weeks after the birth of her baby. She had no past psychiatric history and no social or relationship difficulties. Within 12 days of birth she visited her GP complaining of depressed mood and difficulty bonding with her baby. Despite this being a much-wanted pregnancy, she discussed giving her baby up for adoption. She repeated this desire to her health visitor a month later and seemed distant from her baby at her 6-week check. A week before her death, she said she didn't love her baby and that it had taken over her life. However her husband described her following other family members around, as they cared for the baby, to make sure everything was done correctly. She talked of leaving to go overseas and indicated that she had thoughts of killing herself. The severity and suddenness of her changed mental state was not appreciated and, when she described strategies, albeit likely influenced by her mental state, to resolve the situation, such as giving her baby up or leaving the country, she was dissuaded but no alternative offered to meet her obvious great distress.

New and persistent expressions of incompetency as a mother or estrangement from the infant are 'red flag' symptoms and may be indicators of significant depressive disorder. In some cases, they may reflect psychotic thinking. In the presence of significant illness, such symptoms may be best addressed through inpatient mother and baby care.

Assessing mental health status: grade of assessor

For a number of women, their assessment was by junior healthcare staff, either medical or nursing. The importance of early senior involvement in assessment and management is widely recognised in maternity practice and across many other branches of medicine. Late pregnancy and early postpartum change in mental state, particularly where there is a prior diagnosis of significant mental illness, is a predictable indicator of severe disorder. Junior medical or nursing staff, or those from other disciplines, may not have the breadth of experience to recognise herald symptoms, such as mounting anxiety. They may misattribute symptoms to normal emotional changes associated with childbirth, under-diagnose psychotic disorder, or fail to take into account the natural history of rapid deterioration in postpartum psychosis, which requires early and frequent reassessment. A related finding in one case was that all assessments took place over the telephone, reducing the opportunity for full clinical engagement and evaluation.

A woman died by violent means in late pregnancy. There was a history of a previous psychotic episode which was thought to be drug-related. She had been admitted to antenatal care with medical complications and appeared confused and disorientated. An initial duty psychiatrist assessment appropriately concluded diagnostic uncertainty but when her psychiatric symptoms had not settled and she had developed additional bizarre beliefs about her health, a further duty psychiatrist review concluded that she was not psychotic and routine referral for Community Mental Health Team care was made on discharge. She was seen by a Community Psychiatric Nurse a week later at which point continuing bizarre beliefs and significant distress were noted. She was given a further appointment for two days later but when the team arrived to see her she had already taken her life. The importance of her presentation with significant change in mental state in late pregnancy, against a background of prior psychotic disorder, was not recognised by the junior staff who reviewed her.

There should be an expectation of early consultant psychiatrist involvement in the assessment and management of high-risk women and of women exhibiting sudden alterations in mental state in late pregnancy or the early puerperium.

Use of interpreters

A common theme across this and other specialist areas is the failure to use professional interpreters. For a number of women, relatives were used as interpreters and the woman was never seen alone. In other cases, no attempt was made to seek interpretation despite a clear language barrier. One woman was seen four times and difficulty in completing an adequate assessment repeatedly noted because of the lack of an interpreter, without remedial action being taken.

Women should always have the opportunity of being seen alone and, where there are language barriers, family or friends should not be used as interpreters.

NICE Guideline CG110 Pregnancy and Complex Social Factors (National Institute for Health and Care Excellence 2010)

Management issues

Care by multiple teams

Some women's care was characterised by lack of continuity and care by multiple teams. For a number of women, it was unclear who took overall responsibility for co-ordinating their mental health care. The fragmentation of care poses particular risk at a time where illness may be rapidly evolving and makes it more likely that assessments are made 'in the moment' without reference to changing mental state. There is evidence in a number of cases that different teams were not aware of one another's involvement.

A woman with a past history of depression and overdose died by violent means mid-pregnancy. In the months leading up to her death she had symptoms of psychotic depression. She had overdosed with suicidal intent on two occasions. She was seen by at least five different mental health teams. Her care was fragmented with assessments by different teams reaching multiple conclusions about her diagnosis and level of risk. In one example, on three consecutive days, she was seen by three different services. On the first occasion psychotic symptoms were noted. On the second day 'no role' was identified for the mental health team, as she was judged not at risk of admission. On the third day she was admitted with suicidal thoughts.

A related issue is the involvement of crisis resolution and home treatment teams in the management of pregnant and postnatal women. In many instances this reflects a welcome addition to the provision of high intensity community care for patients with significant mental disorder. However, there

is evidence that these teams may not have the necessary understanding of the distinctive features of severe perinatal mental illness, including the rapidity of change of mental state. The particular circumstances of early postnatal mental illness, where minimising risk and preventing alienation from the baby, through early consideration of joint admission is needed, is well understood by specialist services. Crisis resolution and home treatment teams need additional training if they are to be involved in the management of women at this time.

A woman with no past history of mental illness developed early onset of low mood within days of delivering her first baby. Shortly after postnatal discharge she was returned to hospital by ambulance as her midwife was very concerned that she appeared perplexed, not sleeping, describing vivid dreams of her baby being dead, and had talked of jumping off a bridge. The casualty doctor found a similar presentation and referred her for mental health assessment. She was seen by the crisis team and found to be anxious but with no evidence of clinical depression or psychosis. She was discharged without psychiatric follow-up and died by violent means the next day. There was a lack of awareness of the rapid progression of perinatal illness and a downgrading of early postpartum significant change in mental state.

Women should have continuity of care. Where more than one mental health team is involved, there should be a clearly identified individual who co-ordinates care.

Perinatal mental health clinical networks should be established to develop local services and clear pathways of care to prevent care being fragmented and uncoordinated. Networks should always include specialist addictions services.

Liaison, crisis and home treatment teams require additional support and education in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women.

Guidance (Scottish Intercollegiate Guidelines Network 2012, National Institute for Health and Care Excellence 2014a) recognises that perinatal mental health care is best delivered within networks (Box 3.2) in order to care for women with the range and severity of mental health disorders which occur in the perinatal period. However, it is essential that all services which are part of a network operate in an integrated and collaborative way to ensure that women are not at risk of “falling between the gaps”.

Box 3.2: Perinatal Mental Health Networks

Clinical networks should be established for perinatal mental health services, managed by a coordinating board of healthcare professionals, commissioners, managers, and service users and carers. These networks should provide:

- a specialist multidisciplinary perinatal service in each locality, which provides direct services, consultation and advice to maternity services, other mental health services and community services; in areas of high morbidity these services may be provided by separate specialist perinatal teams
- access to specialist expert advice on the risks and benefits of psychotropic medication during pregnancy and breastfeeding
- clear referral and management protocols for services across all levels of the existing stepped care frameworks for mental health problems, to ensure effective transfer of information and continuity of care
- pathways of care for service users, with defined roles and competencies for all professional groups involved.

Each managed perinatal mental health network should have designated specialist inpatient services and cover a population where there are between 25,000 and 50,000 live births a year, depending on the local psychiatric morbidity rates.

Specialist perinatal inpatient services should:

- provide facilities designed specifically for mothers and babies (typically with 6-12 beds)
- be staffed by specialist perinatal mental health staff
- be staffed to provide appropriate care for babies
- have effective liaison with general medical and mental health services
- have available the full range of therapeutic services
- be closely integrated with community based mental health services to ensure continuity of care and minimum length of stay.

NICE Guideline CG192: Antenatal and Postnatal Mental Health (National Institute for Health and Care Excellence 2014a)

Consideration of inpatient care

For 13 women, where there was clear evidence of significant risk, no consideration was given to hospital admission. In other instances, the possibility of admission to a Mother and Baby Unit (MBU) is recorded but not acted upon. Some women even made a direct appeal themselves to be admitted but emphasis was put on keeping the woman at home despite escalating symptoms. In a few records examined, mention is made of funding considerations in deciding that MBU admission would not be pursued.

A woman who died by violent means two months after the birth of her first baby, felt very estranged from her infant. She asked to be admitted to a mother and baby unit on two occasions but her family resisted joint admission. She then requested admission alone to a general adult ward. She was dissuaded from this by her mental health worker, with emphasis placed on the need for mother and infant to remain together, but no alternative plan was put in place to safeguard her.

A woman died by violent means several months after the birth of her first child. She had a history of anxiety and depression managed in primary care. She developed lowered mood within a fortnight of the delivery. In response to her description of suicidal thoughts of a violent nature she was initially referred for counselling. At further assessments she is described as having daily suicidal thoughts. The mental health team were involved. On three separate occasions she requested admission to hospital, the last three weeks before her death, but there is no evidence that this was ever considered as an option for her.

Given the distinctive modifying effects of pregnancy and the postnatal period, thresholds for joint mother-baby admission are lowered when compared with general psychiatry. This may not be fully understood by non-specialised services.

Admission to mother and baby unit care should be considered where a woman has any of the following:

- rapidly changing mental state,
- suicidal ideation (particularly of a violent nature),
- pervasive guilt or hopelessness,
- significant estrangement from the infant,
- new or persistent beliefs of inadequacy as a mother,
- evidence of psychosis.

Involvement of specialised perinatal mental health services

In this enquiry there were at least 15 maternal suicides where there was involvement of specialised perinatal mental health services. Three women died very shortly after their discharge from mother and baby unit (MBU) care, or whilst on leave. In two cases their care after discharge was undertaken by non-specialised general adult services because the woman lived outside the local catchment area. In all cases there was an inappropriate level of risk management. One further woman died whilst awaiting admission to an MBU, when there was a breakdown of communication of risk.

For the remaining 11 women, their involvement with community perinatal mental health services was, in the main, restricted to advice being given to adult mental health services (usually crisis/home treatment teams). It is unclear, from the information available, what the composition of these perinatal mental health services was, or whether their clinical remit was restricted because of resources. Nonetheless, the care that these women received demonstrated problems with risk assessment, continuity of care, and delayed consideration of MBU admission.

A woman died by violent means a few months after giving birth. She had disclosed her previous history of mental health disorder in late pregnancy. She presented to a new GP postnatally with low mood and anxiety. She was commenced on antidepressants and a referral made to mental health services. Shortly afterwards she attempted suicide and reported intrusive violent images. She was referred to the crisis team but two days later made a further suicide attempt, following which she was discharged again to the care of the crisis/home treatment team with advice from the perinatal team and support and supervision from her family. The content of her intrusive thoughts led to safeguarding concerns and separation from her baby. The focus of her treatment was on cognitive approaches to deal with her intrusive thoughts, despite evidence of psychotic symptoms. She contacted the crisis team prior to her death to express suicidal intent, but had died by the time services arrived.

This woman was not seen by a perinatal psychiatrist and her care was undertaken by the crisis team and an adult psychiatrist. This was despite the fact that there was evidently a local perinatal mental health team. There seems to have been no awareness throughout of the perinatal context the meaning of her symptoms and the likely effect of mother-infant separation on a profoundly depressed woman.

Women admitted to Mother and Baby Units are at particular risk whilst on leave or immediately following discharge, especially where they live out of area and their care is taken on by non-specialised community teams. Mother and Baby Units should be reminded of the importance of ensuring robust aftercare for their patients.

Community perinatal mental health services should be adequately resourced so that they can provide both senior specialist clinical opinion and undertake the care of women with serious perinatal illness until its resolution. Providing a service which solely offers advice or signposting, whilst the care of the woman is undertaken by a general adult team, does not safeguard the woman's condition.

Child loss or threat of loss

Child safeguarding procedures

As identified in previous enquiries, some women died by suicide shortly after decisions were made about removal of their infant or other children into care. While there is a necessary focus on the infant's welfare, this seemed to be linked to under-recognition of vulnerability of the woman, particularly after the child was removed from her care.

Other pregnancy or child loss

A further group of women died by suicide in association with the loss of the pregnancy or infant through termination, miscarriage, stillbirth or neonatal death. One woman died close to the anniversary of an older child's death. Previous studies have shown that women whose babies were stillborn are less likely to report receiving a postnatal check by their GP than women whose babies were not stillborn, despite this being a time when additional support is needed (Redshaw, Rowe et al. 2014, Redshaw and Henderson 2015).

Loss of a child, either by miscarriage, stillbirth and neonatal death or by the child being taken into care increases vulnerability to mental illness for the mother and she should receive additional monitoring and support.

Partner and family involvement

A new theme to emerge in this enquiry relates to the understanding that family members have of the nature and seriousness of the woman's illness, and their involvement in her care. In three women there is evidence that family concerns, and indeed alarm, at their relative's altered behaviour and deteriorating mental state were not acted upon in a more urgent fashion.

A married woman who died by overdose almost a year after the birth of her child developed a range of persecutory beliefs in the context of significant depression. Her beliefs were not explored with other family members and initially taken at face value. She was referred for counselling. Her husband expressed his concerns for her mental state but the extent of her disturbed thinking only became evident at the point of her death.

For some family members, their lack of understanding of the mental illness prevented them from being fully engaged with the treatment plan.

A woman who died by violent means a few weeks after the birth of her first child had no history of mental illness but became low in mood soon after delivery. She avoided contact with services to some extent but staff also accepted reassurances from her husband that he was able to care for her, despite increasing concern for her mental state. Her husband may not have been aware of the seriousness of her condition and would have benefitted from further education so that he could better support his wife to get appropriate help.

In a few further instances, family members were given responsibilities for monitoring and caring for the woman, which were likely to be overwhelming. While families are important partners in care, and have a greater knowledge of the patient than any professional can ever have, they should not be burdened with caring responsibilities beyond their capabilities.

Family members have a crucial role to play in recovery from illness. They know the woman better than professionals do, and despite lack of professional knowledge, may be more able to recognise early changes in mental state. Their views should always be heard and included in the overall patient assessment and management (Worthington, Rooney et al. 2013a, Worthington, Rooney et al. 2013b).

Partners and other family members may require explanation and education regarding maternal mental illness and its accompanying risks.

(Worthington, Rooney et al. 2013a, Worthington, Rooney et al. 2013b)

In some circumstances, a partner or other family member may not fully understand the seriousness of the condition and resist professional engagement. This needs to be handled sensitively with time invested in explaining the nature and risks associated with the particular patient presentation, using written and internet resources where useful. If admission is considered, offering the opportunity to visit, or see a video of, the MBU may help to destigmatise care. However, professionals should always prioritise the safety and care of the patient, even where, on rare occasions, this conflicts with a family's wishes.

Substance misuse

In addition to the 14 women who died by suicide and also misused substances, there were a further 58 women who died in relation to drug or alcohol misuse. The overwhelming majority misused multiple substances, with alcohol use alone being relatively unusual.

About 1% of all pregnant women are estimated to have problem drug use and 1% have problem alcohol use (Advisory Council on the Misuse of Drugs 2011). All except one of the women reviewed for the purposes of this chapter had been identified in pregnancy. Two of them were booked for midwifery-led care despite a clear history of drug or alcohol misuse. The NICE antenatal and postnatal mental health guideline (National Institute for Health and Care Excellence 2014a) recommends that all women are screened for alcohol and drug misuse at booking. Many women at risk could be reluctant to admit to these problems because of the fear that their child would be removed. However in the group of women who died failure to identify their substance use was not a significant issue.

Management

Pregnancy is a window of opportunity to engage in treatment and women, including substance misusers, want the best for their babies. Hence women with a history of drug and alcohol misuse may accept treatment at this time, especially if they feel it may improve their chances of keeping their babies. The NICE antenatal and postnatal mental health guideline (National Institute for Health and Care Excellence 2014a) recommends that women with alcohol or drug misuse are offered brief interventions and referred to a specialist substance misuse service for advice and treatment.

Women who engage in methadone treatment programmes during pregnancy improve the outcomes for their baby (National Institute for Health and Care Excellence 2010). However, there is little evidence regarding the benefit of opiate detoxification programmes during pregnancy and there may be a number of risks, particularly in the first trimester (Heberlein, Leggio et al. 2012). For this reason, opiate maintenance therapies are seen as standard management, with detoxification used for those who refuse maintenance. Importantly, it is recognised that there is a risk of accidental overdose in women who stop or reduce drug misuse in pregnancy but start misusing again after childbirth.

It is unclear how many women received opiate detoxification, but this was not without problems:

One woman was admitted for a three-week inpatient accelerated detoxification from her substance misuse treatment after discussion with her substance misuse worker and social worker. She died 5 days after discharge from an overdose.

Severe and multiple deprivation (SMD)

All the women who died primarily from drug misuse were vulnerable in multiple ways, with substance misuse being only one of their many problems, as illustrated by the following vignette:

A single woman, who was using street drugs in addition to a methadone programme, became pregnant unintentionally and booked late. She had a history of childhood and domestic abuse, alcohol abuse, depression and self-harm, had one child in care, was homeless and had a criminal conviction. During pregnancy her care was coordinated by a specialist substance misuse midwife with input from social care and a consultant obstetrician; advice was given by telephone by a nurse at an addictions service. She repeatedly missed antenatal appointments and each time the midwife made contact and arranged to visit her at home. A pre-birth case conference was held and a decision was made to take the baby into care immediately after birth. She delivered preterm and went home after a few hours. After delivery she was discharged by the midwife at 14 days and it was hard for social services to maintain contact with her; when they called at her home she was usually out. The health visitor was not involved because the child was in care. Four weeks later she died after an apparent overdose of methadone, heroin and cocaine.

The care given to this woman during pregnancy was good; she had a specialist substance misuse midwife who made great efforts to engage and support her; followed her up after not attending appointments; took advice about her substitution therapy from addictions services and liaised with social care to provide appropriate child safeguarding. However, at 14 days the midwife who had provided holistic care withdrew, just around the time the child was taken into care. Thereafter the woman did not want to engage with social care who had removed her child. No-one was really interested in her after the baby was considered safe. This theme was also identified amongst the women who died between six weeks and a year after the end of pregnancy and is explored further in chapter 7.

There were many other women who died that had multiple individuals and agencies involved in their care. For a number of women, as noted in other chapters of this and previous reports, no-one took overall responsibility for care.

Consider ways of ensuring that, for each woman who misuses substances:

- progress is tracked through the relevant agencies involved in her care
- notes from the different agencies involved in her care are combined into a single document
- there is a coordinated care plan.

Offer the woman a named midwife or doctor who has specialised knowledge of, and experience in, the care of women who misuse substances, and provide a direct-line telephone number for the named midwife or doctor

NICE guideline CG110: Pregnancy and complex social factors (National Institute for Health and Care Excellence 2010)

The NICE pregnancy and complex social factors guideline (National Institute for Health and Care Excellence 2010) covers management for pregnant women with substance misuse and recommends ways of trying to keep women engaged in services, but it does not cover the postnatal period (when most women died), nor does it consider women with both substance misuse and mental health problems.

There is a need for evidence to inform the national guideline covering pregnancy and postnatal care for women with complex and multiple mental, physical and social factors.

Child safeguarding

Substance misuse is a frequent cause of care proceedings. Analysis of Serious Case Reviews 2009–2011 in England showed that parental substance misuse was apparent in 42 per cent of families (Brandon, Sidebotham et al. 2012). It appears that the children of the women who died were protected by child safeguarding processes. However, the evidence here shows that the safeguarding process does not take into account the needs of the mother who has lost her child.

It is almost as though these women are ignored, overlooked and they are treated as "hopeless" cases.

There should be clear local pathways between maternity, addiction and mental health services for rapid access to specialist addiction services.

Health professionals in addiction and maternity services should have an assertive approach to sustaining engagement with substance misusing women.

Those engaged in child safeguarding procedures should recognise that this is a time of greater vulnerability for the mother.

Physical illness

Mental capacity issues

Three women had probable compromised ability to make decisions about their physical treatment. None had an assessment of capacity despite each refusing intervention. There is available legislation in each jurisdiction of the UK and Ireland to ensure adequate treatment where a patient lacks capacity to give informed consent. This was not used for these women.

A woman who had long-standing substance misuse and multiple medical problems, including a diagnosis of HIV-related dementia, died shortly after an early pregnancy loss. In the month before her death she was judged to require inpatient management of her worsening physical health but she declined. While it was commented that she required an assessment of her capacity, this was not undertaken and she was allowed to make decisions about her care which are likely to have hastened her decline.

All healthcare staff have a duty to ensure that patients have the mental capacity to make decisions regarding their care. Where there is doubt, an assessment of capacity should be undertaken. Further information and guidance on assessing capacity can be found at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/348440/OPG603-Health-care-workers-MCA-decisions.pdf (England & Wales);

http://www.gov.scot/Resource/Doc/217194/0058194.pdf (Scotland)

Local reviews and paucity of psychiatric returns

For many women, it was very difficult to ascertain whether a local review into care had taken place. The number of returns of psychiatric reports was extremely poor and, in contrast to maternity casefiles, it was exceptional to have psychiatric records made available to the enquiry. Few completed mental health returns were received and, in the majority of cases reviewed in the enquiry, assessors had to rely on GP and maternity reports. Where reviews of care were available to the enquiry, they frequently overlooked the specific and, at times, predictable risks faced by women with significant maternal mental illness and so did not allow for lessons to be learned.

Psychiatrists may not be aware of their obligation to complete a report on any cases of death in pregnancy or the first postpartum year, but there was also evidence of non-engagement by mental health trusts in the process of making notes available to the enquiry. This is in direct contrast to the co-operation usual to maternity staff and hospitals.

Investigations into deaths from psychiatric causes at any stage during pregnancy and the first postnatal year should be multi-agency and involve all the services that cared for the woman.

Mental Health Services should publicise the findings of this report and its procedures widely among mental health staff in order to highlight the messages directly relevant to improving care for pregnant and postpartum women with mental health problems.

3.5. Conclusions

Improvements in care which may have made a difference to outcome were noted in almost half of all women who died by suicide (table 3.5). Improvements in care were noted for a further 17% of women, and the records were insufficient to classify care for 19% of women, usually because mental health records were unavailable or not provided by mental health services. This highlights the importance of raising awareness of the Confidential Enquiry into Maternal Deaths amongst mental health staff and services. There is clear evidence of an ongoing need to ensure that relevant mental health history is shared between primary care, maternity and mental health services in order that women can receive the appropriate care they need on the basis of an informed risk assessment of their mental health needs. Maternity, mental health and primary care staff should be aware of the 'red flag' symptoms newly identified in this chapter. Allied to the gaps in perinatal mental health service provision identified by other work (Everyone's Business Campaign 2014, NSPCC Scotland 2015), this Enquiry has identified gaps in training of crisis/home care teams in the understanding of the particular distinctive features and risks of perinatal mental illness. This emphasises further the critical importance of specialised perinatal mental health care to prevent women dying in the future.

Table 3.5: Classification of care received by women who died as a result of psychiatric causes and for whom case notes were available for a detailed review, UK and Ireland 2009-13

Care classification	Suicide (n=93) Frequency (%)	Substance misuse (n=29) Frequency (%)	Total* (n=124) Frequency (%)
Good care	17 (18)	9 (32)	27 (22)
Improvements to care were noted which would not have made a difference to outcome	17 (18)	10 (36)	27 (22)
Improvements to care were noted which would have made a difference to outcome	48 (51)	6 (21)	55 (44)
Insufficient information to classify	12 (13)	3 (11)	15 (12)

*Total includes two women who died from other mental health-related causes

4. Prevention and treatment of thrombosis and thromboembolism

Cathy Nelson-Piercy on behalf of the MBRRACE-UK thrombosis and thromboembolism chapter writing group

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4.1. Key messages

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. Risk assessment should be repeated if the woman is admitted to hospital for any reason or develops other intercurrent problems. Risk assessment should be repeated again intrapartum or immediately postpartum.

Hospitals should develop and women should be offered patient information sheets about venous thromboembolism prevention, diagnosis and treatment.

The first thromboprophylactic dose of low molecular weight heparin should be given as soon as possible after delivery provided there are no obstetric concerns regarding postpartum haemorrhage and regional analgesia has not been used.

Prescription for the entire postnatal course of low molecular weight heparin should be issued in secondary care. This will help ensure that women receive the full course without the need to visit their GP to obtain another prescription. This also provides a double safety net, since the prescription will be checked by a hospital pharmacist, who ensures the correct weight appropriate dose is dispensed.

Dizziness and episodes of collapse/loss of consciousness are symptoms of pulmonary embolism.

Predictive tools for pulmonary embolism used outside pregnancy to determine the need for radiological investigation, such as the Wells score, are not validated for and should not be used in pregnancy.

Pregnant and postpartum women presenting to the Emergency Department with medical problems should be discussed with a member of the maternity medical team. This should ensure appropriate investigations and treatments for pulmonary embolism are not withheld and prophylaxis is prescribed where appropriate.

4.2. Background

Pregnancy and the postpartum state increase the risk of venous thromboembolism (VTE). As noted in the recent green-top guideline from the Royal College of Obstetricians and Gynaecologists (Royal College of Obstetricians and Gynaecologists 2015a), although the relative risk of VTE in pregnancy is increased 4-6 fold (Heit, Kobbervig et al. 2005, Sultan, West et al. 2012) and this is increased further in the postnatal period (Sultan, West et al. 2012), the absolute risk is low with an incidence of only about 1 in 1000 (Heit, Kobbervig et al. 2005, Jacobsen, Skjeldestad et al. 2008). Previous Confidential Enquiry reports have attributed the fall in the maternal death rate from VTE during the 2000s to better recognition of women at risk and more widespread use of thromboprophylaxis (Lewis, Cantwell et al. 2011). However, in the 2010-12 triennium, and as indicated in this report in 2011-13, VTE is once again the leading cause of direct maternal death. This is possibly due to an increase in the at risk population, but also, as highlighted below, this may be associated with a need to improve recognition of risk and hence thromboprophylaxis.

The Royal College of Obstetricians and Gynaecologists published updated guidance for both the acute management and prevention of VTE in pregnancy in April 2015 (Royal College of Obstetricians and Gynaecologists 2015b, Royal College of Obstetricians and Gynaecologists 2015a). This new guidance was not therefore in

operation at the time the women considered in this chapter died and therefore in places care has been compared with the guidelines previously in place. However, recommendations for future care made in this chapter refer to the updated guidance.

4.3. Summary of the key findings 2009-13

The women who died

There were 64 maternal deaths from venous thromboembolism (2009-2013) considered in this chapter. There were 43 women who died from pulmonary embolism during pregnancy or up to six weeks following the end of pregnancy. The assessors considered that PE occurring more than six months after the end of pregnancy was unlikely to be related to pregnancy, thus for the purposes of this chapter, the care of 13 women who died from PE between six weeks and six months postpartum was also considered. The care of eight women who died from cerebral vein thrombosis was also examined (of which three were late deaths). There were therefore 48 deaths from VTE during pregnancy or up to six weeks after the end of pregnancy. The maternal mortality rate from VTE in the UK was 1.26 per 100,000 maternities in 2009-11, 1.08 for 2010-12 and 1.01 for 2011-13.

In the 48 women who died from VTE during or up to six weeks after pregnancy, the thromboses occurred antenatally in 24 women (50%) (although some of these women died after delivery), and in 24 postnatally (50%). Of the 24 women who had postnatal events, 50% had been delivered by caesarean section (9 women had been delivered by emergency caesarean section, 3 by elective caesarean section), 10 delivered vaginally and two after surgical procedures in early pregnancy. Of the 24 women who died antenatally, 50% (12) died in the 1st trimester, 25% (6) in the second trimester and 25% (6) in the third trimester.

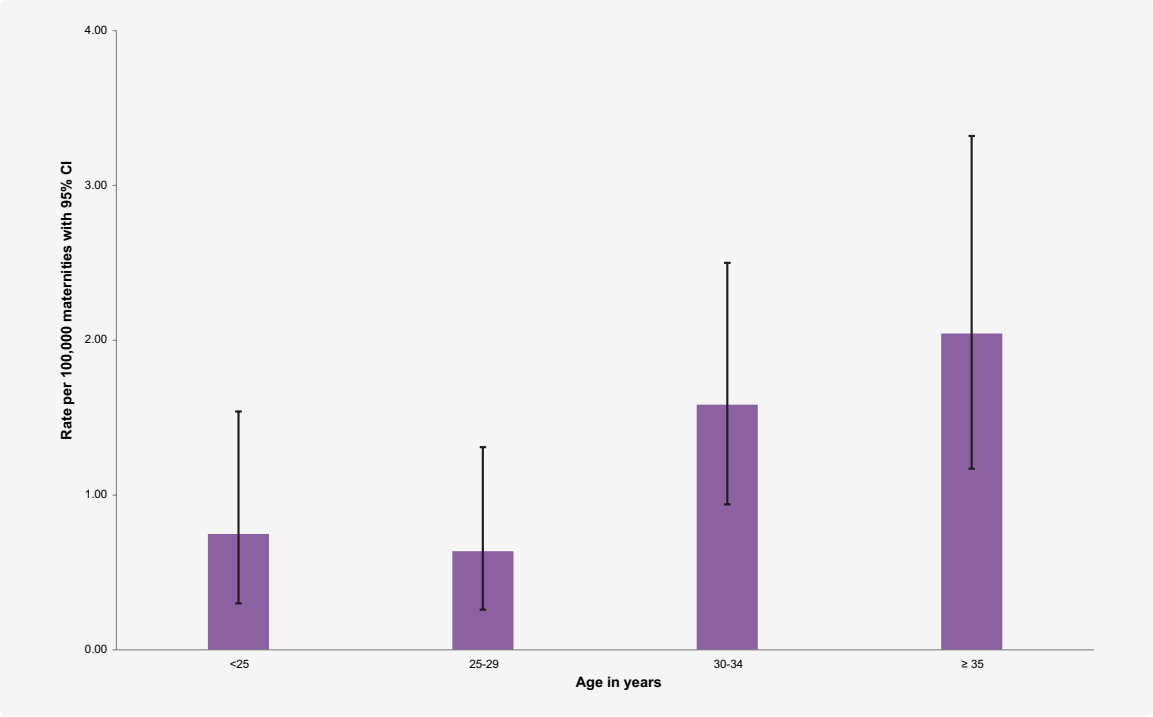
Risk factors

Of the women who died during pregnancy and up to six weeks after the end of pregnancy, 8 women (17%) had no identifiable risk factors for VTE, 6 had one risk factor, 10 had two risk factors, 13 had three risk factors, 6 had four, and 5 had five or more (3 had five, 1 had seven and 1 had eight).

53% (34) of the women who died from VTE were overweight or obese; 38% (24) of the women were obese (11% (8) had a BMI ≥ 40), and 16% (10) were overweight. The maternal mortality rate due to VTE increased with maternal age (Figure 4.1).

In 54% (26) of the women who died during pregnancy or in the six weeks postpartum improvements in care which may have made a difference to outcome were identified by assessors. The care of 52% (25) of women was not compliant with the RCOG obstetric thromboprophylaxis guideline current at the time of their deaths.

Figure 4.1: Maternal deaths from VTE by age among women who died during pregnancy or up to six weeks postpartum (n=48), UK and Ireland 2009-13



4.4. Overview of care and lessons to be learned

Antenatal risk assessment

A woman with multiple risk factors for venous thromboembolism including age, obesity, high parity, smoking and pre-eclampsia was admitted on multiple occasions during her pregnancy with chest tightness and breathlessness in the second trimester. She was never risk assessed and therefore never received low molecular weight heparin thromboprophylaxis and, despite a fall in blood pressure and oxygen saturation immediately after an emergency caesarean delivery, pulmonary embolism was not considered. She died soon after.

Risk assessment for venous thrombosis (VTE) should be undertaken at booking and repeated at any hospital admission, intrapartum or immediately postpartum and before discharge from hospital

RCOG Green-top Guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

Diagnosis / Deaths in first trimester

Twelve women died from VTE in the first trimester, and therefore before any formal booking or risk assessment could be carried out.

Two women with risk factors for venous thromboembolism died from thrombosis in the first trimester having presented to the emergency department, one with leg pain and one with chest symptoms, and found to have D dimers over 20 fold higher than the upper limit of normal. In both women the result was erroneously attributed to pregnancy. A negative leg Doppler was assumed to exclude a DVT despite clinical suspicion and a very high D dimer. Further presentations to the GP with leg pain did not prompt a re-evaluation of the possibility of DVT. When a DVT was finally diagnosed an inadequate treatment dose of low molecular weight heparin was prescribed. In one woman, referred by the GP with suspected pulmonary embolism, a diagnosis of chest infection was made despite a clear chest examination and the very abnormal D dimer. A chest x-ray was not performed with a comment that unless necessary it should be withheld because of the pregnancy. The obstetric team were not informed despite the GP having alerted them to the woman's referral and the suspected diagnosis.

Even though D dimer measurement is not routinely recommended in pregnancy, if it is measured, a very high level should not be attributed solely to pregnancy especially in the first trimester/early pregnancy. Furthermore the negative predictive value of D-dimer is not sufficient to exclude DVT with a negative result in pregnancy.

Pregnant and postpartum women presenting to the emergency department with medical problems should be discussed with a member of the maternity medical team. Units should have appropriate pathways in place. This should ensure appropriate investigations and treatments for PE are not withheld, risk assessment undertaken and prophylaxis is prescribed where appropriate.

It is important to note that the Wells score is not appropriate for use even in early pregnancy and as yet there are no clear clinical prediction scores validated for use in the pregnant or postpartum woman (Konstantinides, Torbicki et al. 2014, Goodacre, Nelson-Piercy et al. 2015). The results of the DiPEP study may provide information to address this in the future (UK Clinical Research Network 2014).

Minimising the risk of peripartum and postnatal VTE in women at high risk of VTE who have required antenatal LMWH prophylaxis or therapy

A young woman who was appropriately receiving low molecular weight heparin throughout pregnancy had her induction of labour delayed. A careful plan for postnatal thromboprophylaxis had been made but this was not followed partly because of a postpartum haemorrhage. In total there was a four-day hiatus in her low molecular weight heparin prophylaxis and she died of thrombosis two weeks postpartum.

Women at high risk of thrombosis who have been on prophylaxis or therapy in the antenatal period require careful planning of their delivery to keep the period of time without LMWH administration to a minimum. Therapeutic and prophylactic LMWH doses are delayed before caesarean section or induction of labour to limit bleeding risks at delivery and to allow for safe regional analgesia/anaesthesia. All members of the clinical team on labour wards need to be mindful that if inductions or planned caesarean sections are delayed this risks prolonged gaps in women receiving LMWH which can be dangerous. Every effort should be made to prioritize these high-risk women.

If prolonged delays (more than 6-12 hours) in delivery of women receiving antenatal LMWH prophylaxis or treatment are unavoidable then LMWH should be given in the meantime and the procedure should be re-scheduled.

Timing, initiation and dosing of postnatal thromboprophylaxis

A morbidly obese woman was not given any thromboprophylaxis antenatally. After an elective caesarean section she was prescribed low molecular weight heparin in an inadequate dose. No doses were received for over 24 hours; she was then prescribed and given the correct dose for her weight but was discharged on day two with only half the weight-appropriate dose as there was an error on the outpatient prescription. She developed a wound infection and died from a pulmonary embolus a few weeks postpartum.

This woman had very severe obesity and readers are reminded that a BMI of ≥ 40 scores 2 points on the risk assessment detailed in the current green-top guideline (see Appendix B) (Royal College of Obstetricians and Gynaecologists 2015a).

Women with a BMI ≥40 score 2 points on the RCOG guideline for thromboprophylaxis in pregnancy and therefore all need postnatal thromboprophylaxis regardless of mode of delivery.

RCOG Green-top Guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

A morbidly obese woman who gained a significant amount of weight during the pregnancy was prescribed an inadequate dose of low molecular weight heparin at the end of pregnancy when she became immobile. Following an elective caesarean delivery, she received the correct weight-appropriate dose but upon discharge this was inadvertently halved. Furthermore she was only given a prescription to cover two weeks although it was intended that the GP prescribe another four weeks of prophylaxis. This did not happen. She contacted her GP a total of four times with leg pain before a referral to hospital as an outpatient was made. She collapsed en route to hospital, was thrombolysed but died a week later within a month of delivery.

This woman's death illustrates the importance of reweighing obese women and providing seamless communication between secondary and primary care in the postnatal period. Community midwives have a role during the postnatal visits in ensuring that women have the correct dose and adequate supply of LMWH and that there is good concordance with the injections based on women understanding their importance. Clear advice also needs to be given about the length of time anti-embolism stockings (AES) should be worn, and reinforced by community midwives who should document their use. This could be included in a patient information sheet about the symptoms and signs of DVT/PE which all women should receive.

Maternal weight in obese women should be re-measured in the third trimester to allow appropriate plans to be made for equipment and personnel required during labour and delivery.

Re-measurement of weight on admission to delivery suite will facilitate dose calculation of drugs required during labour. A weight after delivery may also be necessary to guide dose calculation for women requiring postnatal medication (e.g. thromboprophylaxis), but a need for re-weighing should not delay the administration of thromboprophylaxis. Weighing scales should be routinely accessible in all delivery settings to enable the assessment of weight.

CMACE/RCOG Joint Guideline: Management of Women with Obesity in Pregnancy (Royal College of Obstetricians and Gynaecologists 2010a)

There should be a low threshold for Doppler US of the leg veins in women who complain of unilateral leg/calf pain especially in the puerperium.

A morbidly obese woman died from pulmonary embolism in the puerperium. She did not receive postnatal thromboprophylaxis despite undergoing a repair of a third degree tear in theatre under spinal anaesthesia.

Any operative procedure should be considered an additional risk factor in the puerperium

(Royal College of Obstetricians and Gynaecologists 2015a) (See Appendix B)

An obese parous woman who smoked until pregnancy was admitted with pregnancy complications in the second trimester. Although risk assessed on admission she did not fulfil the then criteria for low molecular weight heparin despite remaining an inpatient for 8 weeks. Following caesarean delivery the first dose of low molecular weight heparin was delayed for 18 hours and a further dose was omitted during her postnatal stay. In the second postnatal week when she was still in hospital she complained of shortness of breath and feeling unwell. There was a delay obtaining medical review and when found to be tachycardic with an abnormal ECG the only investigation planned was a full blood count. She collapsed a few hours later having become more tachycardic and had a cardiac arrest while awaiting transfer to an acute hospital. She was not thrombolysed as her pulmonary embolism was not diagnosed.

The additional risk associated with smoking may persist for several weeks after stopping and thus women should be considered as smokers for antenatal risk assessment if they gave up immediately prior to, or during early pregnancy.

New onset tachycardia together with a new complaint of shortness of breath mandates further investigation for PE. The significance of sinus tachycardia and right heart strain on the ECG were not appreciated. Escalation and involvement of doctors confident in interpreting ECGs is essential.

Starting thromboprophylaxis after delivery

There were four women who died after there had been significant delays in receipt of their first prophylactic dose of LMWH. When prescribing the first dose of LMWH after delivery, prolonged delays in administration should be avoided – in particular adhering to fixed ward drug rounds can lead to protracted delays, so a stipulated time for the first dose should be given and adhered to. The first postnatal dose of LMWH should be administered as soon as possible and within 6-8 hours after delivery (taking into account the need to wait 4 hours after removal of the epidural catheter or post spinal). Charting / prescribing of this first dose and an agreed time of administration is the responsibility of the anaesthetist for women delivered in theatre, and should form part of the WHO surgical safety checklist at the end of the delivery / operation. Individual obstetric units should develop local protocols to facilitate this, taking into the account the timing of drug rounds on the labour and postnatal wards. The timing of the second dose may be slightly flexible to facilitate this; for example, subsequent doses can be safely given 8-12 hours later for twice daily treatment and 20-24 hours later for once daily prophylaxis to fit in with the timing of drug rounds.

One parous woman died in the first week postpartum following an emergency caesarean delivery. For obstetric reasons low molecular weight heparin was appropriately withheld for clinical reasons, but no mechanical means of thromboprophylaxis were employed.

When there are surgical reasons to delay, or contraindications to LMWH, the use of mechanical methods and intermittent pneumatic compression devices (e.g. Flowtron boots) should be considered to mitigate the otherwise increased risks these women face. Although there is an absence of evidence assessing outcomes following their use in these circumstances, they may be of benefit while the mother is immobile. All women should be kept well hydrated and as mobile as their circumstances allow.

The use of properly applied anti-embolism stockings of appropriate size that provide graduated compression with a calf pressure of 14–15 mmHg is recommended in pregnancy and the puerperium for women who are hospitalised and have a contraindication to LMWH.

RCOG Green-top Guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

Postnatal risk assessment

Nine women died in the postnatal period in whom thrombophylaxis assessments and/or VTE prophylaxis were inadequate or lacking altogether. Some of these women died despite

good plans having been made in the antenatal period. If plans are made antenatally for postnatal thromboprophylaxis, systems need to be in place to ensure that these plans are explained to and agreed with the woman, clearly documented (perhaps in the postnatal section of the handheld notes, or flagged on the electronic record), and enacted. VTE risk assessments (including re-weighing) should be performed carefully and deliberately before transfer to the postnatal ward with adequate handover given, or before a 6 hour discharge home.

Postnatal prescription of LMWH

On several occasions, despite being assessed as at high risk and needing a prolonged course of LMWH postnatally, women were not given the full prescription prior to discharge from hospital; the expectation was for the GP to prescribe the remainder of the course. This creates extra barriers for the woman who may find it hard to visit her GP and then the pharmacy to obtain the LMWH. The prescriber of the drug should take clinical responsibility for the prescription: correct dosages, compliance, instruction in use and risks and benefits. This is clearly the secondary care prescriber. Women requiring postnatal LMWH should therefore be prescribed and issued with the entire supply by the obstetric unit to avoid inadvertent gaps or premature cessation of thromboprophylaxis and in the interests of patient safety and preventing premature death. There are clear pressures from hospitals for more prescribing to move to primary care because of financial considerations. Local policy needs to be clear in order that there are no disputes about who funds the provision of LMWH, at the expense of the patient. In addition the community midwife should check that the woman has the correct supply and understands the importance of completing the course of injections. This is even more pertinent since the updated guidelines from the RCOG recommend 10 days LMWH for those at intermediate risk in the postnatal period (Royal College of Obstetricians and Gynaecologists 2015a).

Prescriptions for the entire postnatal course of LMWH should be issued in secondary care. This will help ensure that women receive the full course without the need to visit their GP to obtain another prescription. This also provides a double safety net since the prescription will be checked by a hospital pharmacist, who ensures the correct weight-appropriate dose is dispensed.

Diagnosis of PE

A young woman died from a pulmonary embolism a few weeks after an emergency caesarean section. She fainted at home, was assessed in the Emergency Department, found to have sinus tachycardia on ECG but discharged. During a later admission pulmonary embolism was still not considered as a cause of her symptoms despite another episode of dizziness on the ward.

Dizziness and episodes of collapse / loss of consciousness can be symptoms of PE

RCOG Green-top guideline 37b (Royal College of Obstetricians and Gynaecologists 2015b)

A morbidly obese parous woman presented to the emergency department in early pregnancy with a three day history of calf pain radiating to her thigh and some chest tightness. She was assessed using the Wells score to have a low pretest probability of pulmonary embolism and was therefore not investigated

Predictive tools for pulmonary embolism used outside pregnancy to determine the need for radiological investigation, such as the Wells score, are not validated for and should not be used in pregnancy. Clinicians should be aware that, at present, there is no evidence to support the use of pretest probability assessment in the management of acute VTE in pregnancy.

RCOG Green-top guideline 37b (Royal College of Obstetricians and Gynaecologists 2015b)

An older, obese, parous, woman who smoked received only four days of thromboprophylaxis with low molecular weight heparin after an emergency caesarean delivery, despite having a postpartum haemorrhage necessitating a blood transfusion, and a wound infection. Her risk was not correctly assessed and no mention of venous thromboembolism risk was made in her discharge letter. She contacted her GP surgery complaining of respiratory symptoms and could not attend the surgery. An exacerbation of her asthma was diagnosed as a result of the telephone call but she was not seen in person as her risk of venous thromboembolism was not appreciated. She died two weeks later of multiple pulmonary emboli. She had also been prescribed the combined oral contraceptive pill.

Accurate risk assessment postnatally would have given the woman described above a score of eight (see appendix) and she should have received 6 weeks of LMWH prophylaxis. Both haemorrhage (Sultan, West et al. 2012) and transfusion (Liu, Rouleau et al. 2009) are independent risk factors for VTE increasing the risk 3 to 4 fold.

PE cannot be diagnosed or excluded over the telephone; women with suspicious symptoms should be seen in person for assessment

Box 4.1: Symptoms of venous thromboembolism

Deep Vein Thrombosis

Painful swollen leg (lower leg or whole leg)

Redness / oedema of leg

Left iliac fossa / groin / buttock pain

Non-specific lower abdominal pain

Pulmonary Embolism

Chest pain (sudden onset)

Breathlessness (sudden onset)

Dizziness

Syncope or collapse

Tachycardia

Hypoxia

Cerebral Vein Thrombosis

Headache

Seizures

Postnatal prescription of Combined Oral Contraceptive Pill (COCP)

There were two late deaths where women had been prescribed the COCP. Oestrogen containing oral contraceptives can be prescribed three weeks postpartum if the woman is not breast feeding but they should be avoided in women with BMI ≥ 35 (Faculty of Sexual and Reproductive Healthcare 2009). Other risk factors for VTE, such as immobility, which includes post-surgical immobility following caesarean section, should be considered before prescribing the COCP postnatally (Faculty of Sexual and Reproductive Healthcare 2009). It is important to note, however, that, unlike RCOG thromboprophylaxis guidance, current Medical Eligibility Criteria for Contraceptive Use (UKMEC) guidance only considers one risk factor at a time, not multiple factors occurring at the same time. GPs may not be aware of all the risk factors women have at three week postpartum if the communication on discharge has been inadequate.

Liaison with a specialist contraceptive provider may be required prior to advising on postpartum COCP use by women with multiple risk factors, since current Medical Eligibility Criteria for Contraceptive Use (UKMEC) guidance only considers single risk factors.

Women already receiving LMWH

A woman with previous venous thromboembolism and thrombophilia on longterm warfarin was converted to low molecular weight heparin in early pregnancy. She presented to her GP with buttock pain and no action was taken. When she presented to the Emergency Department with shortness of breath a chest x-ray was found to be normal but despite hypoxia, no further imaging was performed because pulmonary embolism was considered unlikely given that she was already receiving a treatment dose of low molecular weight heparin.

An obese woman who had an emergency caesarean section for pre-eclampsia and was prescribed the correct dose of low molecular weight heparin had two postnatal visits to the emergency department with pleuritic pain. On the first she did not wait to be seen and at the second pulmonary embolism was thought unlikely as her chest x-ray was normal and she was receiving low molecular weight heparin. She died towards the end of the puerperium.

VTE can develop despite the use of thromboprophylactic or treatment doses of LMWH, so women taking LMWH who present with clinical features suggestive of a PE should be appropriately investigated.

A normal chest x-ray does not exclude PE.

Pre-pregnancy counselling for women with previous venous thromboembolism

A woman with recurrent previous venous thromboembolism taking long-term warfarin was advised against using the combined oral contraceptive pill. She stopped her warfarin when she found out she was pregnant. After four days she was prescribed a prophylactic dose of low molecular weight heparin. She died of a pulmonary embolism in the first trimester.

The assessors could find no evidence that this woman had received pre-pregnancy counselling other than being advised to stop warfarin and switch to LMWH when she got pregnant. The prophylactic LMWH was an inadequate dose.

Women with pre-existing medical conditions should have pre-pregnancy counselling by doctors with experience of managing their disorder in pregnancy.

Saving Lives, Improving Mothers' Care 2014 (Knight, Kenyon et al. 2014)

Women on long-term warfarin pre-pregnancy require pre–pregnancy counselling and high prophylactic or full anticoagulant doses of LMWH in pregnancy

RCOG Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

Thrombolysis

A woman who had been admitted with hyperemesis and severe dehydration received thromboprophylaxis during her admission but died three weeks later from a massive pulmonary embolism. She had been thrombolysed.

This woman had exemplary resuscitation and the appropriate use of thrombolysis. The RCOG updated thromboprophylaxis guideline (Royal College of Obstetricians and Gynaecologists 2015a) (see Appendix B) recommends LMWH only during admission with hyperemesis but ongoing dehydration, immobility or the presence of other risk factors for VTE should prompt consideration of continuation of LMWH.

An overweight woman who smoked presented to her GP with dizziness and breathlessness in mid-pregnancy. Several days later she collapsed at home, had a cardiac arrest in the ambulance, and on arrival at hospital underwent perimortem caesarean section. The clinical diagnosis was pulmonary embolism but thrombolysis was not given as there was concern about bleeding after the perimortem caesarean section.

Neither pregnancy, caesarean section delivery or the immediate postpartum state are absolute contraindications to thrombolysis.

Saving Lives, Improving Mothers' Care 2014 (Knight, Kenyon et al. 2014)

Box 4.2 Recommendations from RCOG Green-top guideline 37b Thromboembolic Disease in Pregnancy and the Puerperium: Acute Management (Royal College of Obstetricians and Gynaecologists 2015b)

In clinically suspected DVT or PE, treatment with low-molecular-weight heparin (LMWH) should be commenced immediately until the diagnosis is excluded by objective testing, unless treatment is strongly contraindicated.

In suspected massive PE, the on-call medical team should be contacted immediately. An urgent portable echocardiogram or CTPA within 1 hour of presentation should be arranged. If massive PE is confirmed, or in extreme circumstances prior to confirmation, immediate thrombolysis should be considered.

Multidisciplinary communication

An older multiparous woman with previous venous thromboembolism was diagnosed as having a chest infection when she presented to her GP in early pregnancy with cough and pleuritic chest pain. Even when subsequently admitted via the Emergency Department because of more chest pain, pulmonary embolism was not initially considered and low molecular weight heparin was not given. CTPA was not done because of pregnancy. Pulmonary embolism was diagnosed a few days later after an echocardiogram. She was treated with therapeutic low molecular weight heparin, which was interrupted for a surgical termination of pregnancy. She died from a recurrent PE. The local review of her care concluded that the low molecular weight heparin should not have been interrupted.

This woman's care required careful multidisciplinary planning and management. If she had been discussed with obstetric staff when she presented to the Emergency Department, a CTPA would not have been withheld. The risk of bleeding from a surgical termination of pregnancy under general anaesthetic is low and smaller than the risk of further VTE in a woman with previous recurrent and current VTE. Discussion between haematology, physicians, gynaecologists and anaesthetists may have led to a different plan.

Cerebral venous thrombosis (CVT)

Two women died during pregnancy, four in the six weeks after pregnancy and a further two between six weeks and a year after delivery.

A woman presented antenatally with a headache and was found to have a visual field defect. A CT was not originally performed but following a delay this was found to be normal. Cerebral venous thrombosis was diagnosed at autopsy.

Brain CT may not diagnose cerebral venous thrombosis. CT venography or MR venography is required.

One woman who presented with a seizure and preceding headache was assumed to have eclampsia. There was a delay obtaining a neurological or neurosurgical opinion. Another woman also had seizures. Although severe headache is the commonest presentation of CVT, seizures are a well described feature and CVT needs to be remembered in the differential diagnosis of postpartum headache and seizures, for which the commonest explanation is likely to be postpartum eclampsia. (Lewis, Cantwell et al. 2011)

4.5. Conclusions

More than four fifths of the women who died from VTE between 2009 and 2013 had recognisable risk factors for thromboembolism. In many cases, these risk factors were either not recognised, or not acted upon. In several instances, miscommunication or missing communication at the secondary-primary care interface led to inadequate thromboprophylaxis which may have prevented some women's deaths. Improvements were noted in the care of almost three quarters of women (Table 4.1). In the light of the ongoing decrease in direct maternal death rates, deaths from venous thromboembolism remain the major group where a decrease is not currently occurring, highlighting the particular importance of careful assessment of individual women's risk of thromboembolism in order to aid prevention.

Table 4.1: Classification of care received by women who died from venous thromboembolism during or with six weeks after the end of pregnancy 2009-13 (n=48)

Classification of care received	Total (n=48) Frequency (%)
Good care	13 (27)
Improvements to care which would have made no difference to outcome	9 (19)
Improvements to care which may have made a difference to outcome	26 (54)

5. Caring for women with cancer in pregnancy or postpartum

Bryn Kemp, Lucy MacKillop, Adrian Yoong and Malcolm Griffiths on behalf of the MBRRACE-UK cancer chapter writing group

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Peer review: Alison Jones

5.1. Key messages

Treat cancer the same in pregnancy as in non-pregnant women:

- If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus.
- Treatment for all women with cancer in pregnancy should be the same as for cancer in non-pregnant women, unless these is specific evidence that to do this would cause harm. The same targets for diagnosis and treatment times should apply in pregnant and postpartum women as for non-pregnant women.
- Early multidisciplinary discussions are needed for all pregnant women with a new diagnosis of cancer as well as newly pregnant women with a previous cancer diagnosis. A named individual should be nominated to coordinate care; this is particularly important when care is provided across multiple centres.
- Neurological examination including fundoscopy is mandatory in all women with new onset headaches or headache with atypical symptoms.

Treating cancer does not usually require early delivery:

- Iatrogenic preterm delivery is associated with cognitive impairment and other long-term sequelae for the infant and should be avoided wherever possible.

Advice about the timing of pregnancy after a cancer diagnosis should be individualised and based on the treatment needs and prognosis over time. The risk of recurrence of breast cancer is highest in the two years after treatment and most women with breast cancer should be advised to avoid pregnancy during this time.

If metastatic disease is suspected, the placenta should be sent for urgent histological assessment and newborn follow-up arranged where metastatic disease of the placenta is identified.

5.2. Background

Cancer diagnoses in pregnancy are rare and have a reported incidence of between 1 per 1000 and 2 per 10,000 maternities worldwide (Morice, Uzan et al. 2012b). Although still limited with respect to long-term outcomes, data overall are reassuring with respect to fetal outcomes after chemotherapy exposure in utero (Amant, Loibl et al. 2012, Brenner, Avivi et al. 2012, Morice, Uzan et al. 2012a, Amant, Vandenbroucke et al. 2015, Greene and Longo 2015). Since the majority of maternal cancers have no direct effect upon fetal growth and development, the potential for a successful pregnancy (for the fetus) is high provided that decisions about maternal care are optimised and avoid, where possible, the inappropriate preterm delivery of the fetus.

Although cancer of the breast in the younger age-population in which pregnancy usually occurs tends to be high-grade and oestrogen-receptor-negative; both features associated with a poorer prognosis, the evidence indicates that pregnancy does not worsen the prognosis when age and stage are matched (Amant, von Minckwitz et al. 2013, Royal College of Obstetricians and Gynaecologists 2015c).

Overall, the evidence available to guide clinical decisions for women with cancer in pregnancy is limited; often with contradictory findings (Morice, Uzan et al. 2012b). In the UK, there are relatively few standardised guidelines and care pathways for pregnant women with a cancer diagnosis with those available covering breast (Amant, von Minckwitz et al. 2013, Royal College of Obstetricians and Gynaecologists 2015c) thyroid (British Thyroid Association 2007) and haematological disease (Brenner, Avivi et al. 2012). There are some published guidelines from Europe and a recent series of reviews (Morice, Uzan et al. 2012a). Since the majority of care for pregnant women with cancer is determined by expert consensus within multidisciplinary teams, it is subject to considerable variation. Review of adverse events within the framework of a confidential enquiry provides an essential mechanism to examine trends in the care provided to pregnant women with cancer, as well as to report examples of both high quality and substandard care, along with suggestions for future practice.

5.3. Summary of key findings

The women who died

A total of 180 women died during, or up to one year after pregnancy from malignancy between 2009 and 2013 (Table 5.1) in the UK and Ireland. Twenty-one women died during or up to six weeks after the end of pregnancy in the UK, representing an incidence of 0.53 deaths per 100,000 maternities (95% CI = 0.33 to 0.81). A total of 23 women in the UK and Ireland died during or up to six weeks after the end of pregnancy; 5 of these women died from carcinoma of the breast (3 newly-diagnosed and 2 previously diagnosed), 4 died from lung malignancy (only one of whom smoked), 5 from malignancies of the gastro-intestinal tract, 5 from brain tumours, and 4 from other malignancies. The distribution of organ involvement observed by this enquiry is consistent with national data on cancer related deaths amongst women of the same age group (Cancer Research UK 2012). The care of a further 41 women, who died between six weeks and one year after the end of pregnancy, was reviewed for the purposes of this chapter, bringing the total number of women reviewed to 64.

Of the 64 women: 12 (18.7%) had a pregnancy diagnosis of malignancy; 28 (43.8%) were diagnosed antenatally, and 24 (37.5%) were diagnosed in the postnatal period. Amongst the 40 women diagnosed before delivery, 36 delivered. Of these, 26 (72%) deliveries occurred preterm (<37 weeks' gestation).

The death rate from cancer during or up to one year after pregnancy was higher amongst older women (Table 5.2 and Figure 5.1). These death rates and trends with age are comparable to those in the general female population.

Table 5.1: Timing of maternal malignancy deaths in relation to pregnancy, UK and Ireland 2009-13

Time period of deaths in the pregnancy care pathway	Total (n=180) Frequency (%)
Antenatal period (>20 weeks) or on the day of delivery	5 (2.8)
Postnatal 1 to 42 days after delivery	18 (10.0)
Postnatal more than 6 weeks but less than 3 months after delivery	17 (9.4)
Postnatal 3 months or more but less than 6 months after delivery	36 (20.0)
Postnatal 6 months or more but less than 9 months after delivery	40 (22.2)
Postnatal 9 months or more but less than 12 months after delivery	64 (35.6)

Figure 5.1: Maternal malignancy mortality rates during or up to one year after pregnancy by age, UK and Ireland 2009-13 (n=180)

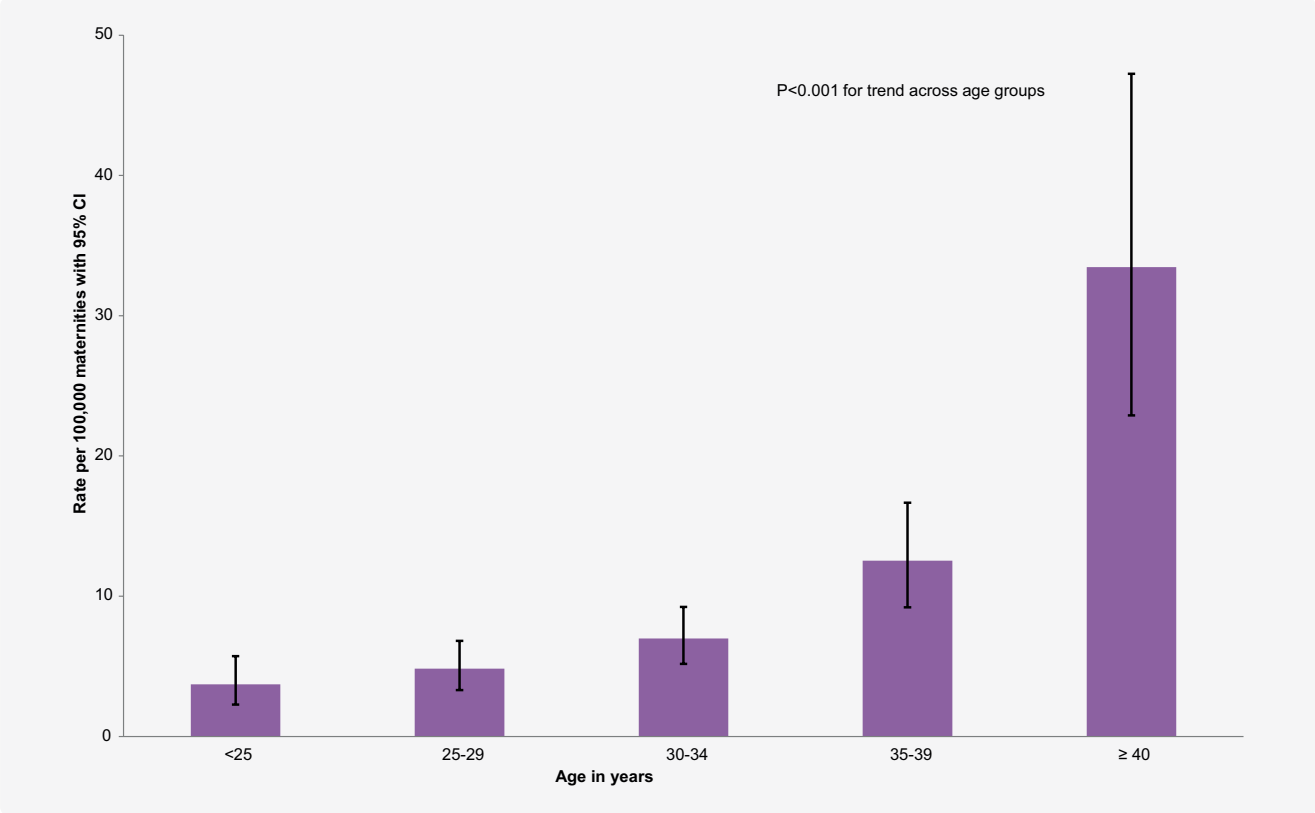

Table 5.2: Maternal malignancy death rates during or up to one year after pregnancy by age, UK and Ireland 2009-13 (n=180)

	Total maternities 2011-13	Total deaths (n=180)	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
Age						
<25	539134	20	3.71	2.27 to 5.73	1 (Ref)	-
25 – 29	662206	32	4.83	3.31 to 6.82	1.30	0.72 to 2.40
30 – 34	701163	49	6.99	5.17 to 9.24	1.88	1.10 to 3.35
35 – 39	374999	47	12.53	9.21 to 16.67	3.38	1.96 to 6.02
≥ 40	95607	32	33.47	22.89 to 47.25	9.02	5.00 to 16.65

Amongst the 157 women who died between 42 days and one year of end of pregnancy, 32 died from carcinoma of the gastrointestinal tract, 21 from breast cancer, 16 from brain cancer, 15 from haematological malignancies, 11 women from cervical cancer, 11 from lung cancer and 11 from skin cancers. A further 8 women died from ovarian cancer, 3 from carcinoma of bone and 16 from other cancers (including renal, endocrinal, bladder, nasopharynx). The primary lesion was not identified in 13 cases.

Only six of the 23 women who died during or in the six weeks after the end of pregnancy had an autopsy and four of these were for medico-legal purposes (Coronial or Fiscal). The assessors agreed with the reported cause of death for all of these women. Amongst the 17 women not undergoing post-mortem examination, reviewers agreed with the cause of death in 11 cases, but considered that 6 women needed a post-mortem to determine their final cause of death. The proportion (35%) of women in whom the cause of death was reported to differ from that assessed may be compared with the figure of 12% observed

for the assessed non-forensic cases in 2009-2012 (Lucas 2015), which covered sepsis, amniotic fluid embolism, haemorrhage, anaesthetic deaths, neurological and other indirect deaths, but not deaths due to malignancy.

Accurate tumour diagnosis is essential to appropriate management and so the correct interpretation of histological findings and adjunctive techniques is crucial. When malignancy presents in an unusual site, the possibility of metastatic disease, including malignant melanoma, should always be considered. Although in most cases, the cause of death will be related to the documented occurrence of the disease, usually widely disseminated, post-mortem examination should be considered to: 1) evaluate the contribution of co-existing medical conditions to the causation of death; 2) assess the efficacy of treatments used in the management of the malignancy, and 3) determine the primary site of origin of tumours where this was not possible before death

5.4. Messages for care

Diagnosis

In a number of women, malignancy was not diagnosed or even suspected until well after the first presentation; and in some cases, not until after delivery. In fact, several women had symptoms that pre-dated pregnancy and were either ignored or not elicited until their cancer diagnosis became clear.

A woman with significant weight loss had nausea and vomiting from the first trimester which persisted into the second trimester. She was treated for hyperemesis gravidarum. She was reviewed in both primary and secondary care multiple times before imaging was requested. Endoscopy and biopsy in the late second trimester confirmed a diagnosis of gastric cancer, at which time it was noted that she had a history prior to pregnancy of several months of epigastric pain, nausea and vomiting, for which she had consulted her GP. This history was not communicated to her secondary care clinicians, and nor was it elicited in secondary care.

Taking a full history and a complete examination is important whatever the route through which a pregnant woman first accesses services.

Clinicians should be alert to the possibility that common, pregnancy specific symptoms may be associated with other pathologies. For example epigastric pain may be a symptom of gastric, oesophageal or pancreatic cancer. Women who present repeatedly with similar problems should be reviewed by senior clinicians to consider an expanded differential diagnosis that includes cancer, particularly when red flag symptoms, such as severe pain are reported. It should be emphasised that symptom management alone is not sufficient, and that an adequate explanation of the underlying cause should be determined, wherever possible. When cancer is suspected, pregnancy should not affect the two week pathway and obtaining of a tissue diagnosis within 30 days (National Institute for Health and Care Excellence 2015b).

A woman with known gallstones presented with abdominal pain on several occasions in pregnancy. After several admissions, an abdominal ultrasound identified gallstones and a large liver mass which was thought to be benign and due to her pregnancy was not further investigated. She had further pain during the remainder of her pregnancy. She died shortly after delivery from metastatic hepatocellular carcinoma.

Uterine enlargement can impair assessment of the abdomen; use of radiological imaging is often, and sometimes inappropriately, restricted for misguided fetal concerns.

If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus. In such instances, a discussion of potential risks and benefits with the woman should be used to determine the most appropriate pathway of investigation.

It was noted in several cases that inappropriate delays in the use of radiological investigations, on the basis of potential harm to the fetus, delayed the diagnosis of cancer.

A woman presented in early pregnancy with epigastric pain and subsequently repeatedly with hip, pelvic and back pain. In the second trimester she developed bilateral leg oedema. She had five abdominal ultrasound scans and repeated scans for DVT which were negative and blood tests showing abnormal tumour markers. There was a repeated focus on common obstetric problems as the cause of her symptoms and when ultrasounds were negative, no other diagnoses or investigations were considered. An MRI in the early third trimester revealed widespread metastatic disease; she was delivered shortly afterwards and transferred to another hospital for management. The involvement of a number of hospitals with specialist services (neonatal and oncology) meant multiple transfers and separation of mother and baby although a visit was arranged shortly before her death a few days later.

While pain in pregnancy from acid reflux and pelvic girdle pain is common, worsening pain requiring repeated admissions to hospital and escalating levels of opiate analgesia should be investigated further. Whilst the assessors felt that this woman's death was probably not preventable, her pain could have been better controlled and her delivery planned to allow her to spend time with her baby.

Repeated presentation with pain and/or pain requiring opiates should be considered a 'red flag' and warrant a thorough assessment of the woman to establish the cause.

Several women presented with severe, recurrent or persisting headaches and did not undergo full neurological examination.

A woman with a history of mental health problems had persistent vomiting in early pregnancy, which continued into the second trimester and did not respond to anti-emetics. She was treated by her GP for labyrinthitis and referred to the ear nose and throat (ENT) team. She was immobile and started low molecular weight thromboprophylaxis. She was admitted on three further occasions and on her final admission reviewed by the ENT team who advised discharge on the basis that there was no ENT cause for her symptoms. She had a persistent, severe frontal headache but did not have a neurological examination or fundoscopy until she collapsed later that day. She was found to have raised intracranial pressure and hydrocephalus due to an intracranial tumour. She died shortly after an emergency caesarean delivery.

Fundoscopy may have led to an earlier diagnosis of this woman's tumour and, again, whilst this is unlikely to have prevented her death, her delivery could have been planned and her pain and other symptoms controlled. This woman's care, along with many others reviewed in this report, shows evidence of the persisting 'silo mentality' amongst specialists in secondary care. Fundoscopy is a basic clinical skill in which all clinicians should be competent. Thus, whilst an ENT cause for her symptoms was excluded, no-one took a holistic view of her symptoms and signs in order to diagnose the cause of her headaches.

Neurological examination including fundoscopy is mandatory in all women with new onset headaches or headache with atypical symptoms. Exclusion of a cause for symptoms in one organ system is insufficient to exclude significant pathology.

Multidisciplinary care

Cancer during pregnancy is not common and pregnancy in women with cancer is very uncommon; especially for certain tumour types. Specialist services have recognised that managing cancer during pregnancy offers the best outlook for both mother and child (Morice, Uzan et al. 2012a, Morice, Uzan et al. 2012b). For this to be most beneficial, multidisciplinary assessment and care planning is essential to determine where the balance lies between the needs of the mother and those of the fetus.

A woman with a rare benign tumour which is known to act in a malignant manner in pregnancy had multiple admissions throughout pregnancy with pain, vomiting, diarrhoea and fever. Care focussed on treating her pain without identifying its cause although she did improve after an initial course of antibiotics. She was cared for in three different hospitals with some time spent investigating a fourth transfer. This resulted in loss of her original obstetric documentation and details of investigations in the preceding weeks which could have highlighted an increasing concern. Her peritonitis, caused by the tumour, was diagnosed at emergency caesarean delivery but both mother and baby died.

The assessors felt that better multidisciplinary planning could have been instituted earlier. This woman's care echoed several of the messages identified in the sepsis chapter in the previous report (Knight, Kenyon et al. 2014), as her sepsis was not diagnosed, with the source of her symptoms only diagnosed incidentally during delivery.

There should be an early multidisciplinary discussion about the care of any woman with complex medical conditions in pregnancy. This is particularly important if the woman is managed across several centres. A named individual needs to take overall responsibility for coordinating her care.

Treatment of malignancy in pregnancy

In several instances, decisions were made to defer treatment (especially chemotherapy) until after delivery. Decisions were often made in favour of iatrogenic preterm delivery, which may have compromised the neonatal and long-term outcome for the baby and led to the potentially avoidable use of neonatal care resources. It was far from clear whether such decisions were either in the maternal or fetal interest. In some instances a delivery was brought forward in response to deterioration in maternal condition, which itself is likely to have been due to delayed treatment.

A woman was diagnosed with an advanced lymphoma in the second trimester. A decision was made to defer chemotherapy. She deteriorated in the third trimester, and, after receiving one cycle of chemotherapy, was delivered preterm by emergency caesarean section. She died a few weeks later.

There is already considerable evidence guiding the use of chemotherapy in pregnancy in general as well as for specific tumour types (Royal College of Obstetricians and Gynaecologists 2015c) and these resources should be used where indicated. Prior to 14 weeks' gestation, the association between chemotherapeutic agents and high rates of fetal abnormalities contraindicates their use (Royal College of Obstetricians and Gynaecologists 2015c). Beyond this gestation, the default treatment pathway for cancer in pregnancy should be the same as in non-pregnant women. In all cases, where there are concerns that to follow this approach would result in harm to mother or fetus, a multidisciplinary review, involving the woman and her family, should consider the pros and cons of treatment plans to reach a balanced decision that reflects the risks and benefits to both mother and fetus. Reviews should take place in a timely manner to avoid inappropriate treatment

delays. Whilst it is recognised that evidence directly relevant to the long-term outcomes of infants exposed to chemotherapy in utero is limited (Amant, Loibl et al. 2012, Amant, von Minckwitz et al. 2013), data on short-term outcomes are reassuring and the absence of data addressing specific questions should not be considered to represent evidence of the potential for harm.

Limited experience of the use in pregnancy of some chemotherapeutic agents, especially more modern ones, may account for concerns about the impact on the fetus. There are some European and US registries but in the UK, the dataset used by the National Cancer Registration Service (in England) does not include details of current or previous pregnancies. Inclusion of a pregnancy field in these data would enhance their utility for providing evidence on the outcomes of chemotherapeutic agents use in pregnancy.

Systemic chemotherapy is safe from the second trimester and should be offered according to protocols defined by the risk of cancer relapse and mortality.

The default treatment pathway for all cancers should be the same as that which would be initiated outside pregnancy, unless there is clear evidence that this is inappropriate. The absence of data on long-term outcomes for children following maternal chemotherapy should not be interpreted as evidence of harm.

Iatrogenic preterm delivery is associated with cognitive impairment and other long-term sequelae for the infant and should be avoided as much as possible. Overall health outcomes of children exposed to chemotherapy in-utero are no different to the general population (Amant, Loibl et al. 2012).

Some women will need complex medical treatment or even hospice-based care. It was noted that in a few cases it was difficult to accommodate the woman and her newborn baby together in the same clinical setting and this should be facilitated.

A woman with known previous breast cancer collapsed at term after an uneventful pregnancy. She was delivered urgently and found subsequently to have multiple cerebral metastases. Negotiation between obstetric, midwifery and medical teams allowed both her and her baby to be transferred to a medical ward for palliative chemotherapy. She subsequently received exemplary multi-disciplinary care with joint treatment decisions between her, her family and her clinicians. She died in a hospice a few months later.

Thrombosis and assessing VTE risk

A woman presented with breathlessness in the second trimester. She was diagnosed with a pulmonary embolism but was also noted to have lung cancer. A decision was made to defer chemotherapy until delivery. She subsequently developed respiratory failure requiring an extremely preterm delivery. She died shortly afterwards. The outcome for her baby is not known.

Six women had venous thromboembolic disease (VTE) complicating their clinical course. In two instances, metastatic disease in addition to extensive pulmonary embolism (PE) was found on CTPA after presentation with signs and symptoms consistent with PE in pregnancy. In one woman, malignancy was found after postnatal extension of an antenatally diagnosed DVT despite adequate anticoagulation. In two women VTE developed in the postpartum period after diagnosis of metastatic cancer and in both cases, thromboprophylaxis was not given in the appropriate dose and/or for the appropriate duration.

A young woman was admitted 7 days after a vaginal delivery with abdominal pain. Investigations revealed metastatic colon cancer. Treatment was started and she was sent home three weeks postpartum without thromboprophylaxis. She presented five weeks postpartum with large bilateral pulmonary emboli.

Malignancy diagnosed within six months of becoming pregnant is an independent risk factor for VTE. RCOG guidance should be followed (antenatal thromboprophylaxis from 28 weeks and postnatal thromboprophylaxis for at least 10 days unless contraindicated (for example if cerebral metastases or blood dyscrasia are present)

(Royal College of Obstetricians and Gynaecologists 2015a).

In some instances, assessors felt that care could have been improved at all stages of a woman's illness.

A previously well women with a family history of colon cancer presented on multiple occasions antenatally with non-specific abdominal pain. There are no records to show any interventions/ investigations were performed. After an uneventful delivery she was readmitted postnatally with abdominal pain at which point investigations revealed she had widespread metastatic colon cancer. Plans were made for chemotherapy and she was discharged home without any thromboprophylaxis. Three weeks later she was readmitted with a pulmonary embolism and died a few weeks subsequently.

Neither the significance of this woman's family history, nor the significance of her repeated presentation were recognised. It is not clear why she did not have any investigations during pregnancy. Her risk of thrombosis was not recognised, leading to her ultimately fatal pulmonary embolism.

Advice to women with a previous malignancy

Several women with a previous diagnosis of malignancy had made a conscious decision to get pregnant, including several who had assisted reproduction. However, in some women with a previous diagnosis of malignancy the pregnancy was unplanned, and they became pregnant relatively quickly after their initial cancer treatment. This emphasises the importance of contraceptive advice to women undergoing or who have recently completed treatment for malignancy. Like clinicians dealing with other chronic medical conditions (such as epilepsy or diabetes) oncologists caring for women of reproductive age need to be aware of the issues relating to contraception and pre-conception counselling in order to allow for the optimal timing and planning of future pregnancies.

Advice on postponement of pregnancy should be individualised and based on treatment needs and prognosis over time. Most women with breast cancer should wait at least two years after treatment, which is when the risk of breast cancer recurrence is highest (Royal College of Obstetricians and Gynaecologists 2015c).

Non-hormonal methods of contraception are recommended for women wishing to avoid pregnancy after treatment of breast cancer (Royal College of Obstetricians and Gynaecologists 2015c).

Metastatic involvement of the placenta can occur in pregnancy; its significance being that there is a consequent risk of fetal involvement. The most common malignancy to spread to the placenta is malignant melanoma, although the more common malignancies in pregnancy, such as carcinomas of the breast, gastro-intestinal tract and lung, leukaemias and lymphomas and other malignancies are also represented (Kraus 2004, Beargen 2005). Transplacental spread to the fetus is even rarer; most cases have involved malignant melanoma, less commonly leukaemias and lymphomas, and very rarely other tumours, including carcinoma of the lung. Nevertheless, it is recommended that the placenta from women with metastatic disease is examined histologically, and that the infant is followed up if placental metastases are found.

If metastatic disease is suspected, the placenta should be sent for urgent histological assessment and if placental metastatic disease is identified, ensure that follow up for the newborn is arranged.

5.5. Conclusions

Whilst the assessors felt that the care of a third of women could be improved, it was felt that this would have made a difference to the woman's outcome in only a small number of instances (Table 5.3). However, improvements in care could improve both women's pain control, and their ability to plan their delivery and subsequent care. The review of the care of these women showed a number of examples of exemplary multidisciplinary care, in which a woman and her family were able to participate fully in treatment decisions. Nevertheless, there were instances, particularly when women were cared for across multiple centres, where a single individual coordinating care would have been helpful. Diagnosis and treatment was delayed by unnecessary avoidance of appropriate investigations and chemotherapy in several cases.

Table 5.3: Classification of care received by women who died as a result of malignancy 2009-13

Care classification	Total (n=64) Frequency (%)
Good care	30 (47)
Improvements to care were noted which would not have made a difference to outcome	17 (27)
Improvements to care were noted which would have made a difference to outcome	3 (5)
Insufficient information	14 (22)

6. Learning from homicides and women who experienced domestic abuse

Marian Knight on behalf of the MBRRACE-UK homicide and domestic abuse chapter writing group

Chapter writing group members: Roch Cantwell, Lisa Elliot, Malcolm Griffiths, Sara Kenyon, Bryn Kemp, Marian Knight, Jenny Kurinczuk, Denise Lightfoot, Manisha Nair, Jim Neilson, Sue Orchard, Sara Paterson-Brown, Judy Shakespeare, Rowan Wilson.

6.1. Key messages

Pregnancy and the puerperium represent periods of higher risk of domestic abuse. Any woman reporting a previous history of domestic abuse should therefore be considered at high risk.

Healthcare professionals need to be alert to the symptoms or signs of domestic abuse and women should be given the opportunity to disclose domestic abuse in an environment in which they feel secure.

Staff in antenatal, postnatal, reproductive care, sexual health, alcohol or drug misuse, mental health, children's and vulnerable adults' services should ask women whether they have experienced domestic abuse and abuse. This should be a routine part of good clinical practice, even where there are no indicators of such abuse.

Information should be clearly displayed in waiting areas and other suitable places about the support on offer for those affected by domestic abuse. This should include information about relevant local and national helplines. These details should be provided in booking information and hand-held maternity notes.

All health professionals caring for women should be aware of the pathway of care once domestic abuse is disclosed, and escalate to senior staff if necessary.

Pregnant and postpartum women presenting to the emergency department repeatedly and/or with unusual symptoms should be discussed with a member of the maternity team and the GP should be informed.

A named midwife should take responsibility and provide the majority of antenatal care for pregnant women who experience domestic abuse.

The care of any woman murdered during or up to one year after pregnancy should be subject to multi-agency Domestic Homicide Review or equivalent.

6.2. Background

One third of women who experience domestic violence are hit for the first time whilst pregnant (Duxbury 2014). Women are known to be at higher risk of domestic abuse leading to homicide when pregnant or postpartum (World Health Organisation 2011), with the woman's partner the most frequent perpetrator. The lifetime prevalence of partner abuse is estimated as 25% for women, and non-partner (family) abuse as 11% (Office for National Statistics 2015). In 2013-14 in England, overall 183 women were murdered, representing an incidence of 0.63 per 100,000 women (Office for National Statistics 2015). It is recognised that women who are experiencing domestic abuse may be at higher risk of abuse during pregnancy and of adverse pregnancy outcome, because they may be prevented from attending antenatal appointments, may be concerned that disclosure of their abuse may worsen their situation and anxious about the reaction of health professionals (National Institute for Health and Care Excellence 2010).

Women who are young, cohabiting, in a relationship where one or both partners has problems with alcohol abuse, have experienced prior sexual or physical abuse and who have children from other relationships are known to be at higher risk of intimate partner violence (Abramsky, Watts et al. 2011). Nevertheless, evidence about potential interventions to prevent or reduce domestic abuse against pregnant women is lacking (Jahanfar, Howard et al. 2014). Women who experience domestic abuse and violence in pregnancy are known to have a number of poor outcomes, including obstetric complications, which could be undetected as women may be unable to attend for antenatal care, as well as preterm labour, antepartum haemorrhage, stillbirth and low birthweight babies.

Female genital mutilation is also recognised internationally as a violation of the human rights of girls and women (World Health Organisation 2014). It is thus considered here in the context of domestic abuse. It is known to be associated with increased obstetric complications including postpartum haemorrhage, perineal trauma and perinatal death (Creighton 2014).

6.3. Summary of the key findings 2009-13

Homicides

Between 2009 and 2013, 13 women were murdered during pregnancy or up to six weeks after their pregnancy, and a further 23 were killed between six weeks and one year after the end of pregnancy, giving a total of 36 women who were murdered. This represents a homicide rate of 0.55 per 100,000 maternities during pregnancy and up to six weeks after the end of pregnancy and 0.97 per 100,000 maternities during pregnancy and up to one year after the end of pregnancy. This is not significantly different from the homicide rate amongst all women aged 16-49 in England and Wales for 2013/14 (86 homicides among 12,279,351 non-pregnant or postpartum women; relative risk 1.30, 95% CI 0.88-1.92), although note the low statistical power of this analysis. Seven women died undelivered in early pregnancy, four women who had potentially viable fetuses died undelivered; a further two babies died with their mother, thus a total of 13 (36%) women died either before delivery or with their babies.

Thirty-one (86%) women were murdered by a partner or former partner, a further 2 (6%) by a family member, and 3 (8%) were random attacks. Twenty women (56%) were killed by stabbing, 9 by strangulation (25%) and 7 (19%) by other methods, predominantly head injury. The characteristics of women are shown in Table 6.1. Surveillance data reported that 8 (24%) of the 33 women who were murdered by a partner or family member were known to have been subject to domestic abuse prior to meeting their violent death. For the 17 women who were murdered by a partner or family member, and in whom data were complete enough to make an assessment at detailed case review, domestic abuse prior to their murder was evident for 12 (71%) women. Thus a history of domestic abuse was not elicited for at least a third of women (4/12) in whom there was clear evidence of domestic abuse and whom a partner or family member subsequently murdered.

Detailed information was not available about 13 women who were murdered between six weeks and one year after the end of pregnancy, thus the care of 23 women was reviewed in detail.

Table 6.1: Characteristics of women who were murdered during and up to one year after the end of pregnancy, UK and Ireland 2009-13

Characteristics of women	Total (n=23*) Frequency (%)
Socio-demographic	
Age	
<20	5 (13.89)
20 – 24	13 (36.11)
25 – 29	7 (19.44)
30 – 34	8 (22.22)
≥35	3 (8.34)
Parity	
0	10 (43.48)
1 to 2	5 (21.74)
≥3	4 (17.39)
Unknown	4 (17.39)
UK citizen	
Yes	21 (91.30)
No	0 (0.00)
Unknown	2 (8.70)
Ethnic group	
White	18 (78.26)
Black or other minority group	5 (31.74)
Unknown	0 (0.00)
Woman's region of birth	
United Kingdom	18 (78.26)
Outside UK	3 (13.04)
Unknown	2 (8.70)
Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)	
First quintile (Least deprived)	3 (13.04)
Second quintile	3 (13.04)
Third quintile	4 (17.39)
Fourth quintile	3 (13.04)
Fifth quintile (Most deprived)	8 (34.78)
Unknown	2 (8.70)
Socioeconomic status (Occupational classification)	
Employed (Either woman or partner)	9 (39.13)
Unemployed (Both)	7 (30.43)
Unknown	7 (30.43)
Able to speak/understand English	
Yes	20 (86.96)
No	2 (8.70)
Unknown	1 (4.35)
Living arrangements	
With partner	13 (56.52)
With parents/extended family	6 (26.09)
Living alone/Others	2 (8.70)
Missing	2 (8.70)
Known to social services	
Yes	8 (34.78)
No	14 (60.87)
Missing	1 (4.35)
Mental health problems or psychiatric disorders	
Yes	4 (17.39)
No	18 (78.26)
Unknown	1 (4.35)

*Analysis of cases reported to the MBRRACE-UK office for which surveillance data was available, except for age where information for all cases was available (n=36 for age)

The homicide rate during or up to one year after pregnancy among white women was 0.69 (95% CI 0.41 to 1.1) per 100,000 maternities compared to 1.8 (95% CI 0.57 to 4.1) per 100,000 among women from black or other ethnic minority groups; the rate in the black or other ethnic minority women was thus two and a half times higher than in white women, although this was not statistically significantly different (RR=2.56, 95% CI = 0.95 to 6.89, p=0.054). Women in the Black or other ethnic minority group all belonged to ethnic groups from the Indian sub-continent (India, Pakistan and Bangladesh).

The perpetrator had a known history of mental health problems in several murders. However, the MBRRACE-UK assessors had limited information about the perpetrators and this information was only available where commented on in local reviews. This may not therefore represent full ascertainment; however, homicides by individuals in recent contact with mental health services are reviewed in detail by the National Confidential Enquiry into Suicide and Homicide by People with Mental Illness (NCISH), and have been noted to be decreasing (National Confidential Enquiry into Suicide and Homicide 2015). NCISH reports that 13% of intimate partner homicides in the UK are perpetrated by mental health patients, similar to the figure of 11% for all homicides (National Confidential Enquiry into Suicide and Homicide 2015); NCISH does not include any information about the pregnancy or post-pregnancy status of the victims. More detailed evaluation of the characteristics of perpetrators may be helpful to identify potential preventive actions but is beyond the scope of the information available to MBRRACE-UK.

Women known to be subject to domestic abuse

Of all women who died between 2009 and 2013 during or up to six weeks after pregnancy, a history of domestic abuse was documented for 25 (5%). The causes of these women's deaths are shown in Table 6.2. Almost half (n=12, 48%) were murdered or died from psychiatric causes. Three quarters of women who died between 2009 and 2013 during or up to six weeks after pregnancy (n=356, 76%) did not appear to have been asked about a history of domestic abuse.

Female genital mutilation

Four women who died between 2009 and 2013 during or up to six week after pregnancy were reported to have had female genital mutilation; this was not considered to be a contributory factor in the death of any of these women, including any of the women who were murdered.

Table 6.2: Causes of death among women who died during or up to six weeks after pregnancy in the UK in 2009-13 and were known to have a history of domestic abuse

Cause of death	Total=25 Frequency (%)
Homicide	6 (24)
Psychiatric causes	6 (24)
Indirect causes	10 (40)
Direct obstetric causes	3 (12)

6.4. Overview of care and lessons to be learned

Facilitating disclosure

As noted above, at least one third of murdered women in whom it was evident on assessment that they had been subject to domestic abuse, did not have any history elicited during their maternity care.

It was not clear that women had been given the opportunity to disclose domestic abuse in the absence of a partner or family member, or given repeated opportunities for disclosure. There were instances where women had never been seen in the absence of a family member who was acting as interpreter. Provision of a neutral interpreter is particularly important to allow for the opportunity to disclose domestic abuse; reliance on telephone interpreting is unlikely to provide the appropriate secure environment to facilitate disclosure

Healthcare professionals need to be alert to the symptoms or signs of domestic abuse and women should be given the opportunity to disclose domestic abuse in an environment in which they feel secure.

NICE Antenatal care guideline CG62 (National Institute for Health and Care Excellence 2008)

Provide women with an interpreter (who may be a link worker or advocate and should not be a member of the woman's family, her legal guardian or her partner) who can communicate with her in her preferred language.

NICE Guideline Pregnancy and complex social factors (National Institute for Health and Care Excellence 2010)

Some women had presented on several occasions with an unusual and or repeated pattern of injury; such presentations should prompt repeated enquiry about domestic abuse when their partner or other family member is not present. The assessors noted that there were a number of occasions in which the woman's partner was verbally aggressive or overly controlling in interactions with maternity staff. Such situations should provide an additional prompt to question the woman on her own about the possibility of domestic abuse.

A woman booked for NHS care in her third trimester having previously had private care. No examination of her social circumstances was undertaken and there was no evidence she had been questioned about domestic abuse. She gave birth shortly after booking and during her postnatal stay her partner was verbally aggressive to staff on several occasions. She was murdered by her partner a few weeks later. Subsequent enquiry revealed several Emergency Department attendances during pregnancy with unusual injuries, none of which had led to concerns being raised by the staff who treated her.

Ensure frontline staff in all services are trained to recognise the indicators of domestic abuse and abuse and can ask relevant questions to help people disclose their past or current experiences of such violence or abuse. The enquiry should be made in private on a one-to-one basis in an environment where the person feels safe, and in a kind, sensitive manner.

Ensure trained staff in antenatal, postnatal, reproductive care, sexual health, alcohol or drug misuse, mental health, children's and vulnerable adults' services ask service users whether they have experienced domestic violence and abuse. This should be a routine part of good clinical practice, even where there are no indicators of such violence and abuse.

NICE Guideline PH50 Domestic violence and abuse (National Institute for Health and Care Excellence 2014b)

Despite opportunities to disclose domestic abuse during routine consultations, women may find it difficult to do so, and evidence of this was seen for several women who were subsequently murdered by their partners. NICE guidance recommends that health care environments should be designed to facilitate disclosure of domestic violence and abuse (National Institute for Health and Care Excellence 2014b). This includes displaying information in waiting areas and other suitable places, such as the backs of toilet doors, about support for those affected by domestic abuse, to include contact details of relevant local and national helplines. The assessors felt that inclusion of this information routinely in booking information and hand-held notes would provide further opportunities for disclosure.

Clearly display information in waiting areas and other suitable places about the support on offer for those affected by domestic violence and abuse. This includes information about relevant local and national helplines (National Institute for Health and Care Excellence 2014b).

These details should be provided in booking information and hand-held maternity notes.

A pregnant woman was murdered by her partner, who had a long history of mental health problems. Her medical records do not give any suggestion of concerns around her home situation. It is not clear whether the appropriate questions were not asked or whether she felt unable to disclose the domestic abuse she was experiencing.

Several of the women who were murdered reported a history of sexual abuse as a child and/or self-harm. Both these factors are known to be associated with abuse against women (World Health Organisation 2011). Raising awareness of these factors, where they are present, with the multidisciplinary team, including the GP, and, where relevant, the psychiatric team, is therefore important to ensure that all staff are sensitive to the possibility of domestic abuse. Communication should be timely, and not dependent on the woman herself i.e. should not be undertaken via a hard copy letter or through the woman's hand-held notes. As noted in the other chapters, direct electronic or telephone communication between professionals would facilitate this.

Staff awareness and training

Communication was not always optimal even where women had disclosed domestic abuse. When a woman has disclosed domestic abuse, it is rarely appropriate for this to be detailed in her hand-held notes. However, some sort of 'coded flag' can be entered in the notes and a flag should be obvious on the hospital information system and GP records so that appropriate coordinated care can be provided. Her GP should be made aware that she is pregnant and that she has experienced domestic abuse. It is important that any safeguarding issues relating to the woman's existing children are also considered. Antenatal services should have clear referral pathways that set out the information and local pathway of care that should be offered to women (National Institute for Health and Care Excellence 2010).

All health professionals caring for women should be aware of the pathway of care once domestic abuse is disclosed, and escalate to senior staff if necessary.

NICE Guideline Pregnancy and complex social factors (National Institute for Health and Care Excellence 2010)

Many areas have established Multi-Agency Safeguarding Hubs (MASHs) to share information, allow for joint decision-making and coordinate intervention (Home Office 2014). Staff working with pregnant and postpartum women who may report domestic abuse should be aware of their local safeguarding team and how to contact them.

Although it is unclear whether improving the identification of domestic abuse improves the long-term outcomes for women, training and the provision of prompts for staff within primary care to recognise domestic abuse and refer has been shown to be cost-effective, using referral of women to specialist services as the primary outcome (Devine, Spencer et al. 2012).

Organisations responsible for training and registration standards and providers of health and social care training should provide different levels of training for different groups of professionals.

Training to provide a universal response should give staff a basic understanding of the dynamics of domestic violence and abuse and its links to mental health and alcohol and drug misuse, along with their legal duties. In addition, it should cover the concept of shame that is associated with 'honour'-based violence and an awareness of diversity and equality issues.

NICE Guideline PH50 Domestic violence and abuse (National Institute for Health and Care Excellence 2014b)

Warning signs

A woman presented on several occasions during pregnancy with apparently minor injuries, but including, on one occasion, a stab wound to the abdomen, apparently self-inflicted. The maternity staff were not made aware of these incidents and no-one identified the pattern as relating to domestic abuse. She was subsequently killed by her partner.

In several instances, women presented repeatedly to services but no-one took a longitudinal view of their care, a theme that is recurrent throughout this report. As a consequence, opportunities to identify the pattern of presentation and its association with domestic abuse was missed. This was noted particularly in relation to unusual presentations to the emergency department.

Pregnant and postpartum women presenting to the emergency department repeatedly and/or with unusual symptoms should be discussed with a member of the maternity team and the GP should be informed.

As with other women with complex needs, the overall coordination of care of women who experience domestic abuse should be undertaken by a single named professional to ensure directed care and support.

A named midwife should take responsibility and provide the majority of antenatal care for pregnant women who experience domestic abuse.

NICE Guideline Pregnancy and complex social factors (National Institute for Health and Care Excellence 2010)

Ongoing care after disclosure

Some women disclosed historical domestic abuse, which subsequently recurred during pregnancy. This re-emphasises the increased risk of domestic abuse during pregnancy and the postpartum period. A woman who reports domestic abuse in the past should therefore still be regarded as high risk.

Pregnancy and the puerperium represent periods of higher risk of domestic abuse. Any woman reporting a previous history of domestic abuse should therefore be considered at high risk.

A woman was admitted at 26 weeks with abdominal pain where she discussed a volatile relationship. An appropriate referral to social services was made. A week later she was assaulted and this incident was reported to the police, who identified previous incidents. She moved out of contact with her partner but this did not prevent her subsequent murder.

The assessors noted that for some women who disclosed domestic abuse even exemplary multi-disciplinary care did not prevent their murder. Staff should therefore not assume that if the police and safeguarding teams are aware of a situation of domestic abuse that the woman concerned is necessarily safe.

Improving care in the future

Local authorities, health services and their strategic partners (including the voluntary and community sectors) should ensure senior officers participate in a local strategic partnership to prevent domestic violence and abuse, along with representatives of frontline practitioners and service users or their representatives.

NICE Guideline PH50 Domestic violence and abuse (National Institute for Health and Care Excellence 2014b)

Full information about the care provided by all agencies was not available for any of the women who were murdered. This partly reflects the role of MBRRACE-UK which is to focus on improvements in NHS maternity care, and also the role of other related organisations such as the National Confidential Inquiry into Suicides and Homicides, which has a remit to investigate homicides committed by individuals who have been in contact with mental health services within the previous 12 months. However, on the few occasions that the MBRRACE-UK team sought information from non-NHS organisations, this was not forthcoming. Obtaining this information would make subsequent MBRRACE-UK reviews more informative.

There was evidence that reviews had been conducted independently by several different organisations, and the assessors felt that, in many cases, a multi-agency review could have been helpful in identifying additional universal messages for future preventive care. Although there has been a statutory requirement to consider a multi-agency Domestic Homicide Review (DHR) in England since April 2011 (see Box 6.1), it was not clear for the majority of the women discussed here, and who died since this requirement came into effect, whether this had been undertaken. Where a review had been undertaken the assessors did not have access to the findings. Over two years (April 2011-March 2013) the Home Office received 54 DHR reports (not limited to pregnant and postpartum women) and noted that information sharing was inadequate in a number of cases. The decision to undertake a DHR is the responsibility of the chair of the local Community Safety Partnership (Home Office 2013); the assessors felt that it would have been valuable to carry out a DHR or equivalent for the 92% of pregnant or postpartum women who were murdered by a partner or family member. If a review is carried out, sharing of information with MBRRACE-UK would allow the lessons to be learned for maternity care to be highlighted as part of the Confidential Enquiry reports.

The care of any woman murdered during or up to one year after pregnancy should be subject to multi-agency Domestic Homicide Review or equivalent.

Home Office Guidance for the Conduct of Domestic Homicide Reviews (Home Office 2013)

Box 6.1: Domestic Homicide Review

A "Domestic Homicide Review" means a review of the circumstances in which the death of a person aged 16 or over has, or appears to have, resulted from violence, abuse or neglect by—

a) a person to whom she was related or with whom she was or had been in an intimate personal relationship, or

b) a member of the same household as herself,

held with a view to identifying the lessons to be learnt from her death.

Home Office Guidance for the Conduct of Domestic Homicide Reviews (Home Office 2013)

6.5. Conclusions

The women who were murdered were almost universally a highly vulnerable group; all women who were murdered by a partner or family member had risk factors for domestic abuse. Given the limited information available to MBRRACE-UK about many of these women's deaths, it was very difficult to classify care and thus proportions of women for whom improvements were noted are not reported here. However, there was clear evidence of many missed opportunities. In many instances there was evidence of a lack of awareness of risk associated with previous sexual abuse, lack of recognition of mental health problems in women's partners and no appreciation of the risk from current or previous domestic abuse. There are multiple occasions for eliciting a history of domestic abuse and other relevant aspects of a woman's history that should be taken in maternity services, and may potentially prevent some of these murders in the future.

7. Messages for the care of women who died between six weeks and a year after pregnancy

Jenny Kurinczuk, David Churchill, Philippa Cox, Denise Lightfoot, Judy Shakespeare, Derek Tuffnell, Cath Williamson, Marian Knight on behalf of the late deaths chapter writing group

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7.1. Key messages

Many of the women who died between six weeks and one year after pregnancy had long-standing and multiple morbidities occurring prior to, during and after pregnancy, and they often led socially complex lives.

Care of these women more than six weeks after birth is currently outside the remit /scope of maternity services, however, there is a clear need for co-ordinated care, including actions for maternity services:

- These women require additional care following discharge from hospital after birth and there is a need for senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians, midwives and all relevant colleagues.
- The postnatal care plan should include the timing of follow up appointments, which should be arranged with the appropriate services before the women is discharged and not left to the general practitioner to arrange.
- A comprehensive summary by the senior obstetrician of the maternity care episode should be sent to the GP who should be responsible for co-ordinating care after discharge from maternity services.
- Repeated presentation to the general practitioner, community midwife (while still under maternity services) health visitor or emergency services should be considered a 'red flag' and warrant a thorough assessment by the GP of all of a woman's problems.

Reviews of maternal deaths occurring up to a year after the end of pregnancy should involve all the agencies (including maternity services) who were involved in the woman's care.

There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, during and after pregnancy.

7.2. Background

Late maternal deaths are those deaths which occur after 42 days and up to one year from the end of the pregnancy and that are the result of 'direct' or 'indirect' maternal causes, regardless of how the pregnancy ended. Following a change in the reporting of late deaths in the MBRRACE-UK reports with the inclusion of all late deaths, it is not possible to compare the number of women who died between six weeks and one year after the end of pregnancy with the UK figures published historically. In the past, other than in 2000-2002, only those late deaths identified and included in the confidential enquiry were counted in the published late maternal mortality figures. Using information from the linkage of the statutory registration of adult female deaths with statutory birth registrations, we have identified all late deaths and included them in the mortality rates for late deaths presented in Table 2.3.

Of the 553 maternal deaths that occurred after 42 days and up to one year after the end of pregnancy in the period 2009-2013, 252 (46%) were reported directly to MBRRACE-UK and 301 (54%) were identified from death certificate information and the linkage of adult female deaths and birth information.

For the purposes of the confidential enquiry, many late deaths were reviewed in relation to the specific cause of death, for example in this report 'late' psychiatric, cancer and thrombosis-related deaths are discussed in the relevant condition-specific chapters. Other 'late' cases were reviewed in the condition-specific chapters in the 2014 report (Knight, Kenyon et al. 2014) and others will be reported in the confidential enquiry chapters in the 2016 report. Themes from some of these cases are also referred to, where relevant to highlight learning points, in this chapter.

Given the large number of 'late' deaths a sample of these deaths was reviewed for the purposes of the confidential enquiry and it is the lessons drawn from these reviews which are reported in this chapter.

7.3. Summary of the key findings 2009-13

Between 2009 and 2013 a total of 553 women died in the period from 42 days and up to one year after their pregnancy ended. About one fifth of them died from 6 weeks to 3 months and around a quarter died in each of the 3 month periods following (Table 7.1).

Cancer related deaths represented the single largest group of late deaths (Figure 7.1 and Table 7.2). Other than to illustrate an example of good communication the findings from the review of the care of these women are reported in the cancer chapter in this report. Mental health-related deaths represent nearly a quarter (23%) of all late deaths in this period and they too are reviewed in the separate mental health chapter, although of note many of the women considered in this 'late' deaths chapter had mental health problems alongside other problems and complications and their care is also considered in this chapter.

Medical conditions account for the majority of the remaining 49% of late deaths of which cardiac conditions represent one in eight; cardiac deaths will be reviewed in detail in the 2016 report. Neurological conditions accounted for 7% of late deaths and the lessons learned from the care of women with neurological conditions were reported in the 2014 report as were the lessons learned from the maternal deaths from sepsis (Knight, Kenyon et al. 2014); deaths from sepsis accounted for 5% of late deaths in this period. A variety of other medical conditions accounted for 12% of late deaths and 4% of late deaths were the result of pulmonary embolism.

Other than for cancer-related death where there is a predominance of deaths after 6 months, the late deaths due to other causes were generally evenly distributed over the four time periods given in Table 7.2.

Table 7.1: Timing of maternal late deaths in relation to the end of pregnancy, UK and Ireland 2009-2013; n = 553

Period from the end of pregnancy	Frequency (%) n=553
More than 6 weeks but less than 3 months	115 (21)
3 months or more but less than 6 months	140 (25)
6 months or more but less than 9 months	154 (28)
9 months or more but less than 12 months	144 (26)

Figure 7.1: Cause of death for women who died in the period 6 weeks to 1 year after the end of pregnancy, UK and Ireland 2009 – 2013; N = 553

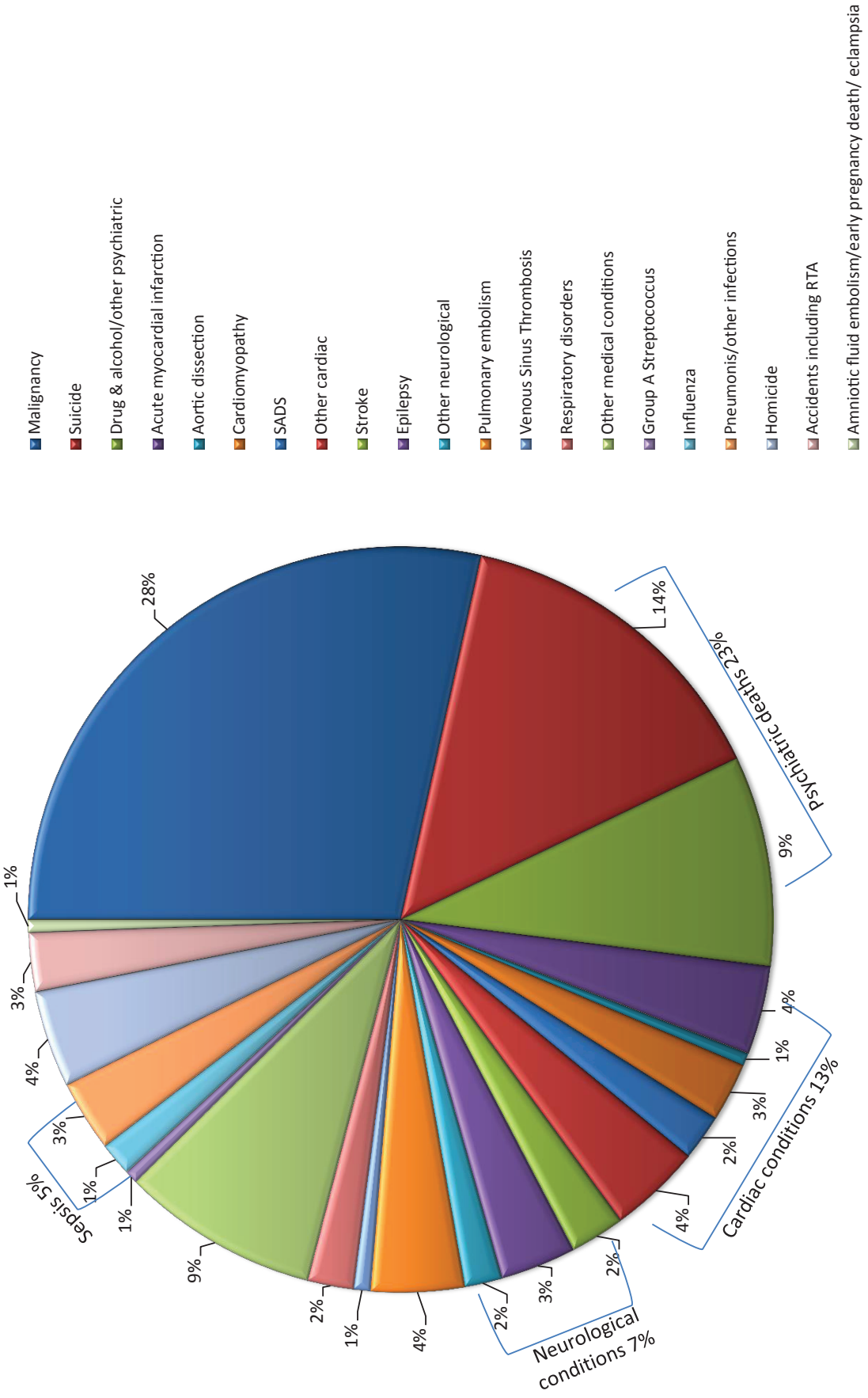

Table 7.2: Timing of late maternal deaths by grouped cause of death, UK and Ireland 2009-13, N=553

Cause of death	Postnatal time period				
	>6 weeks to <3 months n (row %) N=115	≥3 months to <6 months n (row %) N=139	≥6 months to <9 months n (row %) N=154	≥9 months to <12 months n (row %) N=145	Total
Malignancy	17 (11)	36 (23)	40 (25)	64 (41)	157
Psychiatric causes	28 (22)	37 (29)	37 (29)	27 (21)	129
Cardiac conditions	21 (29)	21 (29)	17 (23)	14 (19)	73
Neurological conditions	6 (15)	8 (20)	17 (43)	9 (23)	40
Thrombosis and thromboembolism	8 (31)	7 (27)	5 (19)	6 (23)	26
Respiratory disorders	3 (27)	0 (--)	3 (27)	5 (45)	11
Other non-infectious medical conditions	10 (21)	10 (21)	18 (38)	10 (21)	48
Sepsis	9 (32)	11 (39)	5 (18)	3 (11)	28
Homicide	8 (35)	4 (17)	6 (26)	5 (22)	23
Accidents including RTA	2 (13)	5 (33)	6 (40)	2 (13)	15
Amniotic fluid embolism/early pregnancy death/pre-eclampsia	3 (100)	0 (--)	0 (--)	0 (--)	3

Table 7.3: The socio-demographic characteristics of women who died in the period 6 weeks to 1 year after the end of pregnancy, UK and Ireland 2009-13, N=553

	Total maternities 2011-13	Total deaths n (%)	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
Age						
<20	111805	22 (4)	19.7	12.3 to 29.8	0.98	0.58 to 1.58
20 – 24	427329	86 (16)	20.1	16.1 to 24.9	1 (Ref)	-
25 – 29	662206	120 (21)	18.0	15.0 to 21.7	0.90	0.68 to 1.19
30 – 34	701163	136 (25)	19.4	16.3 to 22.9	0.96	0.73 to 1.28
35 – 39	374999	123 (22)	32.8	27.3 to 39.1	1.63	1.23 to 2.17
≥ 40	95607	59 (11)	61.7	47.0 to 79.6	3.07	2.16 to 4.32
Missing		7 (1)				
IMD Quintiles (England only and for cases with available information n= 289) *						
I (Least deprived/ highest 20%)	291274	49 (15)	16.8	12.5 to 22.2	1 (Ref)	-
II	310685	37 (13)	11.9	8.4 to 16.4	0.71	0.45 to 1.11
III	361339	63 (23)	17.4	13.4 to 22.3	1.04	0.70 to 1.54
IV	442527	48 (17)	10.9	8.0 to 14.4	0.64	0.42 to 0.98
V (Most deprived/ lowest 20%)	543159	92 (32)	16.9	13.7 to 20.8	1.01	0.70 to 1.45

* Postcode data to enable the identification of the index of multiple deprivation (IMD) based on area of residence were not available for 199 women

Women aged 35 and over had a significantly higher maternal mortality rate than women aged 20-24 (Table 7.3). Similar age-related trends in mortality rates are seen in the general female population; for comparison, mortality rates in the general female population in England and Wales (including pregnant, recently pregnant and non-pregnant) are 17.6 per 100,000 women aged 15-24, 36.0 per 100,000 women aged 25-34 and 85.8 per 100,000 women aged 35-44 (Office for National Statistics 2014). The available information for women in England who died indicates that half were living in areas in the bottom two quintiles of deprivation compared with 40% of the general population giving birth.

The majority of women who died between six weeks and one year after pregnancy had more than one medical or mental health condition or social factor complicating their care, in addition to the condition that caused their death. Table 7.4 shows the number of factors experienced by each woman for whom we have detailed information (n=247), including an assessment of 29 different factors: obesity, substance misuse, alcohol dependency, known domestic abuse, known to social services, medical/mental health problems (23 specific conditions), and previous pregnancy problems. Eighty-four percent of women had multiple morbidities or social factors.

Table 7.4 Number of medical, mental health and social factors experienced by women who died between six weeks and one year after the end of pregnancy, UK and Ireland 2009-13

Number of factors experienced by each woman in addition to the condition which caused her death	Number of women (n=247)	Percentage of women
0	39	15.8
1	52	21.1
2	44	17.8
3	40	16.2
4	29	11.7
5	17	6.9
6	12	4.9
7	8	3.2
8	2	0.8
9	1	0.4
10	2	0.8
11	1	0.4

7.4. Overview of care and lessons to be learned

As illustrated by table 7.4, a pervasive theme from the review of the care of many of the women whose death was 'late' is that many of them had multiple morbidities with complex care requirements and as a consequence this chapter specifically focuses on this theme. The majority of messages identified relate to postnatal care, however, a few lessons learned apply to care before and during pregnancy.

General lessons in relation to the care of women with complex clinical conditions or multiple morbidities

Pre-pregnancy Care

The health of women with medical conditions, especially rare disorders and multiple morbidities should be reviewed prior to conception to identify any potential pregnancy-related risks. This will require the recognition in primary care that women with medical conditions and multiple morbidities are at increased risk of complications during pregnancy. Discussion of these issues is needed, including the provision of potentially unsolicited advice about contraception with women of child

bearing age regardless of their current family formation plans, together with referral where specialist advice is required.

A young, overweight woman with a history of treatment in childhood which resulted in impaired cardiac function booked late and attended intermittently for antenatal care. She developed heart failure in late pregnancy and delivery was expedited. After a spell on the intensive care unit she was discharged home. Subsequent deterioration led to cardiac surgery and she died during that admission. There was no evidence that she had received any pre-pregnancy counselling as to the risks of pregnancy given her cardiac condition or a recent assessment of her cardiac function prior to conception.

The care of this woman illustrates the need for the recognition of the potential risks of pregnancy associated with pre-existing medical conditions and the need for appropriate management of the pre-existing condition with advice that conception could be life-threatening. Given the treatment leading to her impaired cardiac function had been many years ago her general practitioner represented the professional linchpin responsible for ensuring that she had access to appropriate advice about the risks of pregnancy given her cardiac condition and she should have had an appropriate pre-pregnancy cardiology assessment.

In the face of a high risk of pregnancy complications and potential death the decision to conceive will be a personal one. However, women with high risk pre-existing medical conditions can only make an informed choice about whether or not to conceive if they are actually informed about the risks. Furthermore, waiting until pregnancy is planned will also fail to provide pre-pregnancy counselling for the approximately 40% of women whose pregnancies are not planned.

Co-ordinated and concerted action is needed at all levels to improve the care of women with medical conditions before, during and after pregnancy.

Saving Lives Improving Mothers' Care 2014 (Knight, Kenyon et al. 2014)

Treatment of infertility

An older, obese, diabetic woman on insulin with a history of polycystic ovary syndrome and multiple miscarriages was on cardiac preventive therapy when she was prescribed clomifene citrate by her general practitioner. Conception resulted in a first trimester miscarriage; she collapsed a number of weeks later and was diagnosed as having a cardiomyopathy. Following in-patient treatment she was discharged home where she died suddenly a month later.

Whilst this woman's cardiac condition may or may not have been related to treatment with clomifene and/or pregnancy, this woman nevertheless illustrates why the treatment of infertility should only be undertaken in specialist centres. Clomifene citrate should only be prescribed where ultrasound monitoring is available (National Institute for Health and Care Excellence 2013) and thus requires specialist infertility service provision and should therefore not be prescribed in general practice. A full assessment of co-existing medical conditions and obstetric history must be undertaken before any form of infertility treatment, including ovulation induction and particularly in vitro fertilisation (IVF), is offered (National Institute for Health and Care Excellence 2013); referral for psychological counselling may be needed where a woman's history suggests that infertility treatment is contraindicated.

Before IVF is started a woman's previous medical and obstetric history must be taken into account when determining what, if any, is the safest embryo transfer strategy.

NICE Fertility: assessment and treatment for people with fertility problems CG156

NICE Guideline 156 Management of fertility problems (National Institute for Health and Care Excellence 2013)

Antenatal care

It is essential that midwives obtain a full medical, obstetric and social history when undertaking the booking assessment. This will enable the

identification of pre-existing physical and mental health conditions, a poor obstetric history and social circumstances which may complicate the pregnancy care; referral to the appropriate specialists and other services can then be expedited. The midwife has a key role to play in coordinating the care for women with multimorbidities as they are able to provide continuity of care through the whole pregnancy (Chief Nursing Officers of England Northern Ireland Scotland and Wales 2010) and the early postnatal period; although depending upon the particular constellation of problems other professionals may take on this coordinating role at various stages of care.

As illustrated by the vignette below there were examples of exemplary antenatal care delivered in complex and challenging circumstances.

A young woman with mental health problems had a history of drug use, drug overdose in the past and self-harm. Her children were in care and an antenatal care order was in place. She was living intermittently in a relationship with a man who was abusive and also a drug user. She attempted to distance herself from this man moving during pregnancy on a number of occasions. She was also trying to build a previously fractured relationship with her family. During pregnancy she attended regularly for antenatal care, responded positively to social services support and attended the drug support services. Supportive and additional midwifery care was provided during pregnancy through an individualised care plan. Her baby was, nevertheless removed into foster care at birth and she committed suicide some months later.

During routine antenatal appointments midwives undertake on-going risk assessment which is vital to identify additional emerging problems. Often, where there are complex issues, women may require other appointments in addition to their routine antenatal care although they may not regularly attend appointments if they have complex social needs. Evidence suggest that women facing complex social problems are deterred from attending antenatal appointments, including booking appointments, because of the perceived negative attitude of healthcare staff, including non-clinical staff such as receptionists (National Institute for Health and Care Excellence 2010).

Organisations should support midwives to initiate a multiagency needs assessment and to be able to provide individual care plans for these women as the traditional models of routine antenatal may not be appropriate.

NICE: Pregnancy and complex social factors: A model for service provision for pregnant women with complex social factors CG110 (National Institute for Health and Care Excellence 2010)

Initial emergency care

Many of the women included in this and other chapters, who died in hospital, initially became unwell elsewhere and often acutely so. Ambulances staffed with paramedics were usually called to transfer the woman to the nearest emergency department (ED). There were many examples of excellent service from these first attenders, who can help deliver babies, provide immediate life support, defibrillate, intubate, cannulate and give drugs for resuscitation. In some cases women were given intravenous thrombolysis at the scene of collapse.

However, there were occasions when potentially life-saving care was withheld inappropriately; for example adrenaline was not given when a breast-feeding woman collapsed despite adrenaline being indicated in this situation. Sometimes the paramedic's interventions were not successful or made the situation worse (e.g. oesophageal intubation) or delayed transport whilst they continued trying to resuscitate the women in situ; however usually the best resuscitative efforts continued alongside rapid transfer to an emergency department for further assessment and treatment. It is clearly important that an emergency department is made aware of an incoming patient who requires on-going resuscitation so that appropriate medical staff can be ready and waiting, this is especially true if the woman is still pregnant, or if the airway has not been secured. There were some examples of a delay in advanced resuscitation in the emergency department whilst additional medical, particularly obstetric, staff were called.

Transfers of care between wards

Having reached a hospital, some women needed transfer to another hospital or to another part of the same hospital for further investigation and treatment. The woman that is most impacted by this is the sick woman not quite ill enough for continuous level 3 care, but with multiple problems and for whom therefore no-one takes a leadership role for her overall responsibility. These women have a tendency to become neglected and overlooked as illustrated by the following vignette, where the women had 15 inter-ward transfers with no one taking overall responsibility for her care.

One woman had 15 inter-ward transfers during a three-week hospital stay before she died. These transfers were as much for bed management as her care needs, which varied between medical and surgical, and meant that she was not adequately cared for anywhere up to the time of her death.

Sometimes staying in one place with staff that know and care about a woman is as vital for her safety and recovery as being moved to another area for different services; when feasible those services should come to the woman (Knight, Kenyon et al. 2014).

Senior decision-making doctors need to assess the woman, and after multi-disciplinary team discussion with senior colleagues in other units, decide on the best place for her on-going care; decisions must include the means and timing of inter- or intra-hospital transfer to ensure that the transfer is carried out safely and to a high standard.

Inter-hospital transfer

Inter-hospital transfer has significant risks for critically ill women; if needed it should occur early, but only after adequate resuscitation and stabilisation, and should be provided by specialised personnel with equipment and expertise that can ensure continued haemodynamic and respiratory support.

The Association of Anaesthetists published a safety guideline on inter-hospital transfer in 2009 (Association of Anaesthetists of Great Britain and Ireland 2009) that details measures required to effect a safe transfer; these have not changed but are not always followed and the reasons for this are complex (Droogh, Smit et al. 2015).

The decision to transfer must not be taken lightly.

A senior doctor, normally a consultant, should therefore be involved in making this decision.

Although transfers are potentially associated with additional risk to patients they can be safely accomplished even in extremely ill patients. Generally, a transfer should not be undertaken until the patient has been resuscitated and stablised:

- it may be necessary to secure the airway and many patients will require a tracheal tube or tracheostomy with appropriate end-tidal carbon dioxide monitoring
- appropriate venous access must be in place and monitoring instituted;
- continuous invasive blood pressure measurement is the best technique for monitoring blood pressure during the transfer of ill patients

Treatment should not be delayed whilst waiting for the transfer

AAGBI Safety Guideline: Inter hospital transfer (Association of Anaesthetists of Great Britain and Ireland 2009)

Transfers within hospitals also cause some of the same problems. Critically ill patients may need transferring between critical care units, scanners and operating theatres, all of which are associated with the risk of destabilisation and deterioration and the requirement for specialised personnel and equipment. Transfers need to be timely, co-ordinated, smooth and well-planned.

Senior review

The importance of senior and experienced clinician involvement in the care of women with multiple and complex problems was apparent in many of the cases reviewed in this chapter. The role of the senior clinician can either be to pick up on the important features of a woman's illness that have not been identified by junior staff or to be the

person who takes an overall, more holistic view of the presenting problem and provides a leadership role in the management.

There still does not seem to be an expectation that women will be reviewed by a senior obstetrician in maternity units within 14 hours of admission, even though this is now a standard for acute care (NCEPOD 2007, Royal College of Physicians London 2007, The Royal College of Surgeons of England 2011, Royal College of Physicians London 2012).

All emergency admissions must be seen and have a thorough clinical assessment by a suitable consultant as soon as possible but at the latest within 14 hours from the time of arrival at hospital.

NHS Services, Seven Days a Week Forum, Clinical Standards. Standard 2.

The earlier involvement of senior clinicians would allow earlier identification of women with complex problems which are often present in women with co-morbidities. The leadership role of the senior clinician is also to identify which other specialists are need to provide input which, at the appropriate level, would cut across a number of the problems identified in the care for some of these women. Senior review can also be very important at the time of discharge. A plan for care up to the next appointment or until review by another discipline with clear communication to the woman, primary and community care practitioners can ensure that any underlying medical and mental health problems are dealt with and followed up. This is particularly important if there has been a change in the woman's condition during the most recent admission. Changes in the medication or the plan for care during the pregnancy or postnatal period benefit from senior input and well-structured communication.

These women require additional care following discharge from hospital after birth and there is a need for senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians and all relevant colleagues.

The postnatal care plan should include the timing of follow up appointments, which should be arranged with the appropriate services before the women is discharged and not left to the general practitioner to arrange.

A comprehensive summary by the senior obstetrician of the maternity care episode should be sent to the GP who should be responsible for co-ordinating care after discharge from maternity services.

Consultant to consultant referrals

Failure to allow consultant-to-consultant referral can hamper efficient postnatal follow-up. In the care of several women it was evident that current systems work against smooth efficient transfer of care. It has been noted in other chapters in this report that there are difficulties with midwives accessing general practice information. An inability to allow consultant obstetricians to refer directly to appropriate consultants in other hospitals or services for postnatal follow up, requiring referral via a triage system or similar clearly led to some women 'slipping through the net'. Likewise there were occasions when GPs were unable to get timely specialist advice for postnatal women as illustrated in the following vignette when the GP was unable to arrange a more timely appointment for neurologist review for a woman with poorly controlled epilepsy.

A woman with severe mental health problems, poorly controlled epilepsy and learning disability was known to social services and had children in care. She had no access to a specialist epilepsy nurse and was receiving an anti-convulsant at a sub-therapeutic dose during pregnancy. After delivery she was given a routine 12-month appointment by her neurologist. She was well known to her GP who had provided intensive, on-going care over many years, even though she was hard to engage. The GP was unable to obtain an earlier appointment with the neurologist. The woman reduced the dose of her anti-convulsant further shortly before her death because she had been fit-free postpartum and felt better than she had for some years. She died from sudden unexpected death in epilepsy (SUDEP), when alone with her baby.

Policy makers and service planners should ensure that there are no barriers in place that prevent clinicians seeking directly the advice and/or involvement of experts in other specialties for women with multiple morbidities, particularly on discharge from maternity care.

Email dialogue between GPs and appropriate consultants should be straightforward, rapid and and universally available.

Arrangements for and delivery of postnatal care

The number of pregnant women with either complex medical or mental health problems, or socially complex lives has increased in recent years. This is against a background of a decrease in the number of routine postnatal visits and contacts by midwives or maternity support staff. Midwives therefore need to be alert to those women who require additional support in the early postnatal period and be able to increase the number of contacts as required. The midwife/ maternity team (as well as the health visitors and FNP) should also be fully aware of services, including support groups, which are available locally and be able to signpost women to these groups.

The default for many women with multimorbidities was to discharge them to the routine model of postnatal care with little consideration of their actual needs. At the very least women who have pre-existing or newly developed medical or mental health comorbidities, substance or alcohol abuse problems, socially complex lives or who have experienced pregnancy complications need specific instructions on the discharge summary which clearly communicate the woman's needs to all individuals and organisations involved in their ongoing care.

A documented, individualised postnatal care plan should be developed with the woman ideally in the antenatal period or as soon as possible after birth. This should include:

- relevant factors from the antenatal, intrapartum and immediate postnatal period
- details of the healthcare professionals involved in her care and that of her baby, including roles and contact details
- plans for the postnatal period

This should be reviewed at each postnatal contact.

A coordinating healthcare professional should be identified for each woman. Based on the changing needs of the woman and baby, this professional is likely to change over time.

NICE Postnatal care guideline CG37 (National Institute for Health and Care Excellence 2006)

Medication whilst breastfeeding

Misinformation about the risks of medication in relation to breastfeeding was a particular issue in some cases. As a consequence appropriate, and in some cases life-saving, medication was withheld from several women in the postnatal period because they were breastfeeding.

A woman in her mid-thirties collapsed with severe chest pain radiating to her left arm two months postpartum. An ambulance was called but both aspirin and glyceryl trinitrate were withheld, as she was breastfeeding. Management was also delayed in hospital and she died from a myocardial infarction four hours after admission.

As noted in the cancer care chapter, the default position when either pregnant or breastfeeding is to prescribe whatever medication would normally be given to a woman who is not pregnant or breastfeeding, unless there is a very clear evidence that it would be detrimental. This is of particular importance when, as in the situation illustrated by the vignette, the treatment may be life-saving.

Treatment for all women in pregnancy and whilst breastfeeding should be the same as for non-pregnant women, unless there is specific evidence that to do so would cause harm.

In some cases routine medication was withheld in the mistaken belief that women should not take certain drugs when breastfeeding. The decision, when breastfeeding, to stop medication that is required for potentially serious maternal diseases should only be taken in the full knowledge of the potential risks of specific drugs in the context of breastfeeding. There are several valuable resources available to inform clinicians, including the UK Drugs in Lactation Advisory Service (UKDILAS) (UK Medicines Information 2015). In particular it is important to continue immunosuppressive drugs such as azathioprine and tacrolimus for which there is research to show limited transfer into breast milk (Sau, Clarke et al. 2007, Bramham, Chusney et al. 2013).

Repeated attempts by women to access care

Several of the women who died in the months following delivery had made repeated attempts to access care, but the pattern of repeated presentation had not been recognised. In many cases these women also had complex social problems and it is not clear whether this distracted staff from the severity of their medical and/or mental health problems.

An obese, hypertensive woman who had pre-eclampsia and gestational diabetes had multiple attendances to the Emergency Department with chest or epigastric pain during the months following her delivery. Her ECGs were abnormal on every occasion and two chest X-rays reported cardiomegaly. She was diagnosed variably with gastritis, musculoskeletal pain and gallstones. An abnormal echocardiogram prompted a cardiology referral but no investigations for coronary ischaemia were undertaken. She died suddenly at home from her hypertensive heart disease one week after her most recent cardiology review.

This woman had multiple attendances at the Emergency Department with chest pain. Some of this pain was atypical but all her ECGs were abnormal. She had evidence of hypertensive heart disease and a history of poor compliance with her anti-hypertensive medication; this appears to have been completely overlooked.

The findings for a number of women echo the reviews of the care of several of the women with sepsis presented in the 2014 report (Churchill, Rodger et al. 2014). Prior to their death from sepsis a number of women had repeatedly presented to services without anyone identifying a pattern of repeated presentations.

Repeated presentation to the emergency department, general practitioner, community midwife, health visitor or to maternity services should be considered a 'red flag' and warrant a thorough assessment of the woman.

This is even more important in women with multiple morbidities.

Sepsis chapter, Saving Lives, Improving Mothers' Care 2014 (Churchill, Rodger et al. 2014)

Communication and information sharing

All too often in cases that have resulted in death or harm to patients, poor information sharing and communication errors are features of the case

reviews (Kirkup 2015). The review of the care of the women who died between six weeks and a year after the end of their pregnancy shows that these problems persist; it is a common theme in all the reports arising from the confidential enquiries into maternal deaths and perinatal deaths in recent times. Clinicians need to be more aware of how and what they are communicating, to whom, and for what reason in order to minimise the problem of poor communication and information sharing (Box 7.1).

Only through effective communication can a genuine understanding of a situation or context be created. This in turn enhances decision-making, team working, situational awareness and leadership. The numerous public inquiries into failures in the health and social care systems and indeed confidential enquiry findings are a testament to the importance of effective information sharing not least the inquiry in Morecambe Bay (Kirkup 2015).

Box 7.1: Communication

To improve communication the person transmitting or providing the information must be aware that four conditions need to be fulfilled for good communication to take place:

1) They must understand the information they are trying to communicate and its significance within the context of the situation;
2) How the information needs to be communicated to generate the impact that is required by in the intended recipient;
3) Why the information being communicated i.e. what mental model do they want to generate in the recipient;
4) Who should and must receive the information so that the intended actions take place.

Chapter 4: Communication; pp 69-91. Safety and the Sharp End. A Guide to Non-Technical Skills. 2008. Eds Rhona Flin, Paul O'Connor, Margaret Crichton. (Flin, O'Connor et al. 2008)

Structural changes in the way clinicians have to work in the modern healthcare setting have made communication between individuals more difficult and have disrupted the continuity of care for patients. The working time directive, limiting the hours doctors are allowed to work, has meant that the 'handover' between shifts has become a problematic area. Increasing sub-specialisation has resulted in the fragmentation of medical specialties causing similar communication problems. Frequent hand-over of patients leads to discontinuity of responsibility and leadership. This 'silo' mentality was observed in the care of several women who died with no single individual taking a holistic view of the woman's health and care.

Where communication is good and information sharing of a high standard, the care provided for women, even in the most tragic circumstances, can be of the highest quality. The vignette below shows how with good teamwork and information sharing the needs of the woman as a whole can be met by all the specialists involved in her treatment.

A woman with previously treated cancer had a recurrence diagnosed in the second trimester of pregnancy. She needed further treatment. A multi-disciplinary team of obstetricians, midwives, neurologists and oncologists drew up a plan, in conjunction with the woman and her partner, to deliver the baby at 30-32 weeks. Unfortunately at 28 weeks she deteriorated. A healthy baby was delivered shortly afterwards. Following a further oncology assessment, it was concluded that she could only be offered palliative chemotherapy. Four and half months after her delivery she died surrounded by her family.

This woman received a very high standard of care. There was excellent communication, information sharing and team working between the staff in the different specialties, obstetrics, midwifery, neurology, oncology, psychology and palliative care, as well as with the woman herself. She was involved in all the decision-making particularly around her end-of-life care and was enabled to die with dignity.

Structured tools that aid communication can be useful in the correct situation to improve communication and information sharing. One such example is the SBAR tool (The Institute for Healthcare improvement and NHS Institute for Innovation and Improvement 2006). The tools help by providing a structure for the person imparting the information to distil the important messages that need to be transmitted. However, these tools are not suitable in all situations and it is still incumbent on the sender to ensure that the four requirements of good communication are met when briefing anyone providing care for women.

Healthcare services should, wherever possible, should use structured communication tools for patient handover so that the clinical information being passed on is complete and relevant.

(Royal College of Obstetricians and Gynaecologists 2010b)

Co-ordinating care

The reviews of the women whose death was 'late' identified many women who had ongoing medical problems and/or developed pregnancy complications, some of these women also had mental health problems, some were known substance users, drank alcohol to excess and lived socially complex lives. They often booked late and were less likely to have received the minimum level of antenatal care. Their multiple morbidities and social factors were clear throughout pregnancy and persisted into the postnatal period until their deaths. It was clear that for some women the clinical staff they interacted with found it very difficult to care for them.

As identified across the chapters in this and previous reports, it was evident that in many cases a single individual did not take overall responsibility to orchestrate the care for many of these women who were expected to attend multiple separate psychiatric, medical and social services appointments. This was commonly the case for the women with the least personal and financial resources to be able meet these expectations. Specialists failed to ensure that other co-morbidities were being adequately treated and that ongoing monitoring of the woman's health was in place. It is vital that doctors retain a 'generalist' overview of the whole patient so that important medical needs are not neglected. It is clear that general practitioners play a pivotal role in integrated care (Royal College of General Practitioners 2014); the recent report issued by the Royal College of Physicians (Future Hospital Commission 2013) recognises that the 'generalist' physician also has an important role to play in the delivery of healthcare. The same can be said of other specialties including obstetrics.

It is to the detriment of patient care for women with multiple morbidities that medicine has become increasingly transactional. The 'routine follow-up' appointment has become frowned upon as unnecessary and wasteful of resources, yet if appropriately targeted could be potentially life-saving. This confidential enquiry suggests an identified need for targeted follow up for specific groups of women including those women who have had complications in pregnancy and other complicating factors, to ensure that their care is being coordinated appropriately. Midwives, obstetricians, health visitors and general practitioners may all be appropriate to fulfil this role, depending upon each individual woman's needs; what is clear is that a single individual must be identified to take a leadership role in this respect.

Targeted follow up must take place for women with complex medical needs, to ensure that the expected recovery has occurred and that the need for any on-going care is being met. A single individual should take a leadership role in this respect.

Women should be offered relevant and timely information to enable them to promote their own and their babies' health and wellbeing and to recognise and respond to problems

NICE Postnatal care guideline CG37 (National Institute for Health and Care Excellence 2006)

Women with multiple morbidities and socially complex lives

Women who live socially complex lives present particular challenges for the organisations and professionals charged with the responsibility for providing care for them both during and after pregnancy. In the context of late maternal deaths these social complexities include living in poverty, being homeless, having children in care, having

an antenatal care order in place for their unborn child, living with an abusive partner, experiencing abuse from other family members and unrelated individuals, having drug and alcohol problems, and contending with mental illness. Added to these problems, women in these situations also frequently have pre-existing medical conditions and/or develop pregnancy complications with postpartum implications.

It was clear from the reviews that some women were provided with good antenatal care in a multiagency setting which supported their access to the care they needed; avoiding the need where possible for multiple appointments in different places at different times with different services. However, following the birth of their baby, the woman's care tended to fragment again, this was often in the context of the baby having been taken into care when social and other services for the woman and her on-going problems were withdrawn.

A woman with mental health problems was a drug user with a history of drug overdose and self-harm in the past. She was on methadone but continued to use drugs on occasion and smoked cigarettes and marijuana throughout her pregnancy. Her children were in care and an antenatal care order was in place for once her baby was born. She was in an abusive relationship and estranged from her extended family. During pregnancy she attended for antenatal care and engaged with social services and drug support. Supportive additional midwifery care and social services support was provided during pregnancy through a multiagency individualised care plan. The baby was placed in foster care at birth; support for the woman ceased three weeks post-partum. She committed suicide 6 months after her baby was born.

Early opportunities to identify the problems faced by vulnerable women were also missed on occasion.

A young, unemployed, single woman attended regularly for antenatal care having booked in the second trimester. She was assessed as low risk and booked for a home birth. On arrival at the home when the woman was in labour the midwife found that despite this being her booking address, she was homeless and staying temporarily with a friend. The decision was made by the attending midwife that the accommodation was unsuitable for a home birth and she was transferred to hospital for delivery. She was discharged back to her temporary accommodation the next day. It later transpired that she had major debts and her benefits had been cancelled just before her baby was born. The fact that she was destitute and homeless was not apparent from the antenatal notes. She committed suicide killing both herself and her baby six months after giving birth.

The situation of this woman illustrates that an incomplete assessment of her circumstances had been made antenatally. Whilst she may have chosen to not disclose her straitened financial status it was, however, only when she was in labour that her homelessness and temporary housing situation was recognised; clearly her 'home' had not been assessed for its suitability as a location for a home birth. Had this assessment been made enquiries as to why she was in this situation may have led to earlier support with her financial and housing problems.

It was also clear some women were expected to battle on with a system which was not sympathetic to the difficulties they might have accessing help. However, in some instances it was also difficult to avoid the feeling that some women were regarded as having lives which were just too chaotic with problems, perhaps perceived as self-created, which made it just too hard to help them.

A woman in her twenties with several children in care died three months after the birth of her baby due to a drug overdose. She had a history of poorly controlled type I diabetes, mental health problems, chronic leg ulceration, illegal drug use and abuse of prescribed medications. This pregnancy was unplanned and she booked late, intensive antenatal care was provided although she frequently failed to attend for appointments; the drug support agency was involved and she was enrolled on the methadone programme. She had several admissions due to hypoglycaemic episodes antenatally and postnatally. Following a normal delivery her baby was placed in foster care. Postnatally she continued to use drugs and was found dead; post-mortem toxicology confirmed her death was due to a multiple drug overdose.

In the context of an increasingly complex maternity population, it is pertinent that the current guidance makes no specific mention of women with multiple morbidities and their complex needs It is not clear whether the NICE guidance on multimorbidity per se, due for publication in September 2016, will include guidance on care for women with multiple morbidities prior to, during or after pregnancy; although pregnant women are not specifically excluded there is no mention of pregnancy in the scope (National Institute for Health and Care Excellence 2015a).

Services must be organized to recognise and provide care for pregnant and postpartum women with multiple morbidities using the best available evidence

There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, and during and after pregnancy.

The women described above illustrate the wide range of agencies involved in care of pregnant and postpartum women with multiple morbidities. In order to learn lessons for future care it is essential that all agencies are involved in reviewing the care of women who die.

Reviews of maternal deaths occurring up to a year after the end of pregnancy should involve all the agencies (including maternity services) who were involved in the woman's care.

7.5. Conclusions

Because of the large number of women who died in the period from 6 weeks to 1 year after their pregnancy it was not possible, nor necessary, to subject all the cases to confidential enquiry in order to learn the lessons for future care. Many common themes were clearly identified. Overall 140 of the women whose deaths were late had case notes available with sufficient information for an in-depth review. The care of just less than a third (31%) of these women was regarded by the assessors as 'good care with no improvements identified' (Table 7.5). About a quarter (26%) of the women were assessed as having received care where improvements were identified but it was considered that the improvements would have made no difference to the outcome. For the remaining two-fifths (43%) improvements to care were identified; and it was judged that these may have made a difference to the outcome. Compared with the assessment of care received by the women who died before 42 days after the end of pregnancy and whose care was reviewed for this report (Table 2.14), the women whose deaths were after 42 days were more likely to have a classification of care indicating there were improvements in care which could have been made (59% versus 69% respectively) and which may have made a difference to the outcome (38% versus 43% respectively), although this difference was not statistically significant.

A feature of many of the women who died in the period from six weeks up to one year after their pregnancy was that they had multiple morbidities and often led socially complex lives. Nevertheless, these women have the right to expect the same standard of care as that provided to women outside of pregnancy in the case of medical and mental health problems, and the same standard of maternity care provided to their pregnant and recently pregnant peers with more straightforward pregnancies. Indeed these women will require more support during pregnancy and postnatally than women with more straightforward pregnancies. Many of the women whose care was reviewed in this chapter had such complex problems, including medical, psychiatric and social, that they required multiagency working and individualised care

plans both antenatally and postnatally. Additional guidance on standards of delivery of this care is needed.

As was evident from the Saving Lives, Improving Mothers' Care report in 2014 (Knight, Kenyon et al. 2014) repeated presentation to the general practitioner, community midwife or emergency services should not be ignored. Repeated postnatal presentation should be considered a 'red flag' and warrants a thorough assessment of all of a woman's problems and not just the presenting symptom.

Table 7.5: Classification of care received for women who died in the period 6 weeks to 1 year after then end of their pregnancy, (2009-13), N=140

Classification of care received	Late deaths (n=140) ł Number (%)
Good care, no improvements identified	43 (31)
Improvements to care identified which would have made no difference to outcome	36 (26)
Improvements to care identified which may have made a difference to outcome	61 (43)

ł Includes all women whose case notes were available with sufficient information for an in-depth review

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Appendix

Appendix A1: Venous thromboembolism – pathological aspects

Sebastian Lucas

At autopsy, massive pulmonary thromboembolism is about the most straightforward scenario that a pathologist can face when investigating a maternal death. It should not be missed, so long as the standard protocol of a high-quality autopsy (for any death) is followed: the pathologist performs the evisceration herself or is present at the table when the anatomical pathology technologist (APT) does so; the heart with lungs are removed en bloc; the proximal pulmonary arteries are opened and inspected before the lungs are separated from the heart; and the right and left pulmonary arteries and all 5 lobar arteries are cut open with scissors to within 1-2cm of the pleurae.

Similarly, when the skull is opened for examination of the brain, the superior, straight, transverse and sigmoid venous sinuses should be opened in all cases, as standard, to check for thrombi (central venous thrombosis, CVT). If a thrombus is found, it should always be submitted for histology, in situ with the adjacent dura and vein, to confirm its pre-mortem nature and to consider its chronology by observing its relation to the endothelium. Although not represented in the current cases, a rare scenario is of large air embolism going to the brain (confirmed by pathognomonic CT imaging in life), causing widespread superficial ischaemic necrosis which then undergoes back-bleeding, and so resembles the cortical haemorrhage of CVT.

Unresolved issues

There are three long-standing problematic issues with pulmonary thromboembolism autopsy pathology:

1. Can the autopsy pathologist identify any thrombophilia risk factors at autopsy, beyond pregnancy, a large uterus, recent caesarean section, cancer, sickle cell disease (James, Jamison et al. 2006), and obesity? Families often wish to know about inheritable risks, when a woman dies suddenly and unexpectedly from PE.

Autopsy blood is of no use for evaluating clotting factors, platelets, D dimers, INR and other standard clotting ratios, and autoimmune disease serology. Bone marrow histology might identify proliferating megakaryocytes, and the kidney and other organs might show features of antiphospholipid syndrome. Theoretically, DNA from blood or spleen could be used to test for Factor V Leiden and other inherited thrombophilic tendencies (MacCallum, Bowles et al. 2014). However, the author has no personal experience of any of these molecular diagnostic processes ever producing a positive result. Stored antenatal serum may be available for serodiagnostic tests.

2. Does a straightforward case of PE diagnosed at autopsy require full examination of the leg and pelvic veins, and histology of the thrombo-emboli?

The classic PE, with granular thrombus and lines of Zahn, is sufficiently characteristic; doubtful cases may be resolvable by histology. Most fatal PEs originate in the internal and external iliac (especially the left side) and femoral veins; these should always be inspected, at least to the proximal femoral vein level, and fragments of remaining thrombus may be seen attached to the vein endothelium – and can be sampled histologically to support their origin location. Traditionally, pathologists open the calf veins (tibial and popliteal), unilaterally or bilaterally, to seek thrombi. But these on their own are not the source of massive fatal PE, and finding clots there or not becomes rather immaterial if the pulmonary artery disease is indisputable. In the rare case of chronic venous embolic pulmonary hypertension, they should be sought.

3. In cases of clinically-suspected PE, but where there are no grossly evident thrombi on careful inspection of the pulmonary arteries at autopsy, is it possible that thrombolysis can remove most or all traces of the embolism?

The issue has been raised in some maternal deaths, where a negative autopsy apparently confounds the pre-mortem diagnosis. It is theoretically possible that clot may be dissolved by perimortem thrombolysis but no pathological data exist to confirm or refute this hypothesis. Fibrinolytic and non-fibrin specific thrombolytics are standard treatment in acute diagnosed and suspected PE. Trials of different agents suggest that in 50-82% of cases, the clots reduce or disappear by two hours post-infusion in survivors (Goldhaber, Kessler et al. 1988, Ferrari, Benhamou et al. 2005). Personal observations by the author of PE fatalities despite thrombolysis indicate large remaining, if sometimes fragmented, thrombi in the pulmonary arteries. Cases of patients, pregnant or not, with convincing CT-angiography-diagnosed pulmonary emboli who have died despite standard thrombolytic therapy and who have convincingly negative arteries at autopsy have yet to be documented.

Do the deaths in the current 2009-12 period shed light on this issue? Six women were thrombolysed following cardio-pulmonary collapse due to suspected massive pulmonary embolism. One had a positive CTPA scan, but no subsequent autopsy. Half of the others had, at autopsy, large proximal pulmonary artery emboli, indistinguishable from PEs found in non-thrombolysed patients; they had died soon after collapse and thrombolysis. One woman who died 8.5 hours after thrombolysis had no gross PE at autopsy, but lung histology showed small distal fragments. The sixth woman died 48 hours after collapse and thrombolysis; no gross PE was seen, but no lung histology was done. This case, where the differential diagnosis rests between VTE and SADS cardiac death, had therefore to be categorised as 'Unascertained'. Lung histology, performed even in obvious cases, can also identify episodes of previous PE, as was the case in two of these women.

In conclusion, it is likely that thrombolysis can remove some of the clot in massive PE. At autopsy in such 'grossly negative' cases, it is important that lung histology be examined to identify either small peripheral fragments, so supporting the diagnosis of PE - or their absence, which would make PE much less likely.

Appendix A2: Placental pathology in women with metastatic disease

Adrian Yoong

By far the most common malignancy to spread to the placenta is malignant melanoma; disproportionate to its frequency in pregnancy. However, the more common malignancies in pregnancy, such as carcinomas of the breast, gastro-intestinal tract and lung, leukaemias and lymphomas and other malignancies are also represented (Kraus 2004, Beargen 2005). Transplacental spread to the fetus is even rarer; most cases have involved malignant melanoma, less commonly leukaemias and lymphomas, and very rarely other tumours, including carcinoma of the lung. Almost all cases of fetal involvement have ended in demise of the fetus.

The comprehensive review by Alexander et al describes a total of 87 cases of placental involvement and/or fetal metastasis, which were discovered in the literature up-to 2002, of which 72 cases reported placental involvement only, 10 cases fetal metastasis only (with no placental examination) and 5 reported both placental involvement and fetal metastasis (Alexander, Samlowski et al. 2003). Malignant melanoma was the cancer most commonly found to involve the placenta (in 31% of cases) and to metastasise to the fetus (in 40% of cases). Of the 24 cases where the placenta was histologically examined and found involved by metastatic melanoma, fetal infant death occurred in 3 cases (up-to 10.25 months after birth), which represents a mortality risk of 12.5%. Interestingly, in all of the 3 fatal cases, "gross metastasis" was identified in the placenta, but of the 9 cases that showed "gross" involvement of the placenta, 3 resulted in fetal death (as just described), but in the other 6 cases, there was no evidence of disease (follow-up up-to 2 years after birth). This has been assumed to suggest that the level of tumour burden in the placenta, at least by itself, poorly correlates with fetal metastasis. It should also be noted, however, that in all 15 cases where the placenta showed "microscopic metastasis" only, there was no evidence of disease in the fetus (follow-up up to 4 years after birth).

In the current study period, 2009-2013, there were 11 late maternal deaths from metastatic melanoma; detailed information is available for three women only. The placenta was examined in two women and the nature of the placenta is unknown in the third, noting that in the latter, the diagnosis of malignant melanoma was made substantially postnatally. In one placenta, a "single focus of involvement" was stated as found, but it is unclear how the placenta was examined (placenta histology report not available). In the second placenta, intervillous collections of melanoma cells were found in 2 of 5 blocks of the placenta, some attached to the villi, although no evidence of invasion of the villi was found and no tumour cells were seen in fetal blood vessels. From the available information, the infants were all alive and well up to six months post-delivery.

It is therefore reasonable to require the pathological examination of the placenta in all cases of pregnant women dying with malignant disease, noting that malignant melanoma is by far the commonest tumour to spread to the placenta and to involve the fetus, although in absolute terms, these are rare events and even more rarely do the more common malignancies occurring in pregnancy affect the placenta and the fetus. There is no up-to-date published guidance in the UK literature regarding placental examination in women with malignancy (Hargitai, Marton et al. 2004). In one case in the literature, 83 parenchymal blocks of an 180mm-diameter placenta were examined, showing intervillous space involvement in 7, noting that "numerous whitish fleshy nodules measuring 2 to 5 mm. in diameter" were seen on gross examination

(Rothman, Cohen et al. 1973). In the only current study case for which sufficient information regarding the placenta is available, 5 blocks of the placenta parenchyma were examined, revealing intervillous space involvement in 2.

It is reasonable to suggest that all focal lesions in the placenta should be examined, together with one random para-central block from each quadrant, in addition to other tissues usually sampled and any further material that the Pathologist considers appropriate in the clinical context or based on the gross appearances of the placenta. While the aim of the examination is to determine the presence of metastatic disease and any other significant pathology, it should be noted that of the 5 melanoma cases in the review by Alexander et al that had villous invasion and tumour emboli in fetal blood vessels, there was fetal metastasis in only 2 and no evidence of disease in the 3 other infants with follow-up periods ranging from 5 months to 1 year, suggesting that placental or fetal vessel invasion may be necessary, but not sufficient for fetal spread. Regarding the corollary, what if there is no histological evidence of malignant involvement of the placenta (or the placenta was not actually examined)? As a guide, according to the findings in the review by Alexander et al, of the 14 cases of fetal metastasis and death, mostly related to metastatic melanoma, but also including lymphomas, leukaemias and carcinomas of the lung, 11 of these cases presented with evidence of tumour involvement within 6 months and all by 20 months, these periods may be shortened by the use of more sensitive investigative techniques, including imaging.

Appendix B: Risk assessment for VTE

Appendix III: Risk assessment for venous thromboembolism (VTE)

- If total score ≥ 4 antenatally, consider thromboprophylaxis from the first trimester.
- If total score 3 antenatally, consider thromboprophylaxis from 28 weeks.
- If total score ≥ 2 postnatally, consider thromboprophylaxis for at least 10 days.
- If admitted to hospital antenatally consider thromboprophylaxis.
- If prolonged admission (≥ 3 days) or readmission to hospital within the puerperium consider thromboprophylaxis.

For patients with an identified bleeding risk, the balance of risks of bleeding and thrombosis should be discussed in consultation with a haematologist with expertise in thrombosis and bleeding in pregnancy.

Risk factors for VTE

Pre-existing risk factors	Tick	Score
Previous VTE (except a single event related to major surgery)		4
Previous VTE provoked by major surgery		3
Known high-risk thrombophilia		3
Medical comorbidities e.g. cancer, heart failure; active systemic lupus erythematosus, inflammatory polyarthropathy or inflammatory bowel disease; nephrotic syndrome; type I diabetes mellitus with nephropathy; sickle cell disease; current intravenous drug user		3
Family history of unprovoked or estrogen-related VTE in first-degree relative		1
Known low-risk thrombophilia (no VTE)		1[a]
Age (> 35 years)		1
Obesity		1 or 2[b]
Parity ≥ 3		1
Smoker		1
Gross varicose veins		1
Obstetric risk factors		
Pre-eclampsia in current pregnancy		1
ART/IVF (antenatal only)		1
Multiple pregnancy		1
Caesarean section in labour		2
Elective caesarean section		1
Mid-cavity or rotational operative delivery		1
Prolonged labour (> 24 hours)		1
PPH (> 1 litre or transfusion)		1
Preterm birth < 37^{+0} weeks in current pregnancy		1
Stillbirth in current pregnancy		1
Transient risk factors		
Any surgical procedure in pregnancy or puerperium except immediate repair of the perineum, e.g. appendicectomy, postpartum sterilisation		3
Hyperemesis		3
OHSS (first trimester only)		4
Current systemic infection		1
Immobility, dehydration		1
TOTAL		

Abbreviations: ART assisted reproductive technology; IVF in vitro fertilisation; OHSS ovarian hyperstimulation syndrome; VTE venous thromboembolism.

[a] If the known low-risk thrombophilia is in a woman with a family history of VTE in a first-degree relative postpartum thromboprophylaxis should be continued for 6 weeks.

[b] BMI ≥ 30 = 1; BMI ≥ 40 = 2

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ISBN 978-0-9931267-3-4

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