

Institution: Cardiff University		
Unit of Assessment: Psychology, Psychiatry and Neuroscience (4)		
Title of case study: New clinical guidelines and specialist mental health services for bipolar women at risk of postpartum psychosis		
Period when the underpinning research was undertaken: 2005 - 2011		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Ian Jones	Clinical Professor	01/10/2003-present
Arianna di Florio	Clinical Senior Lecturer	01/06/2013-present
Elizabeth Forty	Lecturer	01/05/2008-present
Nicholas Craddock	Clinical Professor	01/10/2002-31/03/2014
Period when the claimed impact occurred: 2013 – 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact (indicative maximum 100 words)		
<p>Lack of understanding of individual risk of postpartum psychosis in bipolar women prevented patients from receiving effective, individualised, clinical management designed to prevent severe illness, and even suicide. As part of the largest study of childbirth in women diagnosed with bipolar disorder, Cardiff researchers identified and quantified individual risk factors for postpartum psychosis, including experience from past pregnancies and family history. Findings from this study provided robust evidence for: (a) a new NICE Guideline for clinicians treating bipolar women in the UK; (b) a voluntary sector led campaign for specialist perinatal services resulting in £365M government funding; and (c) training for UK clinicians caring for bipolar women, enhancing their understanding of patients' individual risk of developing postpartum psychosis.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>Postpartum psychosis is a severe psychiatric disorder affecting over 1,400 women in the UK each year. It is characterised by sudden onset and rapid deterioration of symptoms (such as delusions, confusion and severe mood swings), and can lead to severe illness and suicide. In an opinion piece in 2005, Cardiff's Jones and Craddock noted that the Confidential Enquiries into Maternal Deaths (2001) found suicide to be the leading cause of maternal mortality in the UK, frequently linked to an abrupt onset of severe psychotic illness within days of childbirth. The opinion piece further commented that despite being in contact with psychiatric services, none of the women who died had received a detailed risk assessment, formal management plan, or were under close surveillance in the puerperium.</p> <p>While many clinicians recognised that bipolar women were more susceptible to postpartum psychosis than the rest of the population, lack of evidence on the prevalence of postpartum psychosis in bipolar women, and the factors determining individual risk, meant they were unable to provide individualised, targeted care. In addition, specialist services to support bipolar women prior to conception, during pregnancy and after childbirth, were scarce across the UK, with no formal recognition that this was an urgent unmet need.</p> <p>Addressing these gaps, the Cardiff team led a series of studies to expand clinical understanding around individual risk of bipolar women developing postpartum psychosis.</p>		
2.1 Prevalence and onset of postpartum psychosis in women with mood disorders		
<p>The Cardiff team conducted the largest study of postpartum psychosis in women diagnosed with mood disorders [3.1]; specifically, considering 1,785 women (over 3,000 deliveries), grouped by diagnosis (bipolar I, bipolar II and Recurrent Major Depression). For the first time, the study showed a considerably higher risk of postpartum psychosis in bipolar type I women (1 in 5 deliveries versus 1 in 1000 in the general population) with symptoms occurring earlier in the postpartum period compared to women with other forms of bipolar disorder. A further</p>		

study found that women were at particularly high risk for postpartum psychosis in the first two weeks following delivery [3.2].

2.2 Individual risk factors for the onset of postpartum psychosis in bipolar women

In two additional studies [3.3, 3.4], the Cardiff researchers investigated the contribution of previous perinatal history on risk of subsequent postpartum psychosis. They found that:

- women with bipolar type I who experienced postpartum psychosis in their first pregnancy had a 43% risk of postpartum psychosis in their second pregnancy [3.3];
- women with bipolar I who previously experienced less severe episodes of perinatal mood disorder, for example depression without psychosis, or who did not become unwell following a previous pregnancy, had a greatly decreased risk of developing postpartum psychosis (less than 10%) [3.3];
- women with bipolar II disorder who had not experienced a mood episode in the previous perinatal period were at a very low risk of postpartum psychosis (2%) [3.3];
- recurring episodes of postpartum psychosis were likely to be present in a similar way to the first episode (i.e. mania and/or depression) and onset was likely to be at the same time after childbirth [3.3];
- longer first postpartum episodes, and a longer gap between pregnancies, increased likelihood of a second episode of postpartum psychosis [3.4].

Two further Cardiff research studies highlighted the impact of genetic factors in vulnerability to postpartum psychosis in bipolar women [3.5], underlining the importance of family history to better understand risk of severe postpartum episodes and likely recurrence in subsequent pregnancies [3.6].

3. References to the research (indicative maximum of six references)

[3.1] Di Florio A, Forty L, Gordon-Smith K, Heron J, Jones L, Craddock N, Jones I. (2013) Perinatal episodes across the mood disorder spectrum. *JAMA Psychiatry*, 70(2), 168-175. DOI: jamapsychiatry.2013.279

[3.2] Heron J, Gilbert N, Dolman C, Shah S, Craddock N, Jones I. (2008) Early postpartum symptoms in puerperal psychosis. *British Journal of Obstetricians and Gynaecologists*, 115(3), 348-353. DOI: 10.1111/j.1471-0528.2007.01563.x

[3.3] Di Florio A, Gordon-Smith K, Forty L, Kosorok MR, Fraser C, Perry A, Bethell A, Craddock N, Jones L, Jones I. (2018) Stratification of the risk of bipolar disorder recurrences in pregnancy and postpartum. *British Journal of Psychiatry*, 213(3), 542-547. DOI: 10.1192/bjp.2018.92

[3.4] Blackmore ER, Rubinow DR, O'Connor TG, Liu X, Tang W, Craddock N, Jones I. (2013) Reproductive outcomes and risk of subsequent illness in women diagnosed with postpartum psychosis. *Bipolar Disorders*, 15(4), 394-404. DOI: 10.1111/bdi.12071

[3.5] Jones I, Hamshere M, Nangle JM, Bennett P, Green E, Heron J, Segurado R, Lambert D, Holmans P, Corvin A, Owen M, Jones L, Gill M, Craddock N. (2007) Bipolar affective puerperal psychosis: genome-wide significant evidence for linkage to chromosome 16. *American Journal of Psychiatry* 164 (7), 1099-1104. DOI: 10.1176/appi.ajp.164.7.1099

[3.6] Robertson E, Jones I, Haque S, Holder R, Craddock N. (2005) Risk of puerperal and non-puerperal recurrence of illness following bipolar affective puerperal (post-partum) psychosis. *British Journal of Psychiatry*, 186(3), 258-259. DOI: 10.1192/bjp.186.3.258

4. Details of the impact (indicative maximum 750 words)

Cardiff's research provided critical evidence that improved understanding of individual risk of postpartum psychosis in bipolar woman. This included identification of increased risk in individuals with bipolar type I, the importance of family history and prior experience of postpartum psychosis during pregnancy, and the need for improved monitoring and support

of women in the first two weeks after childbirth. This research delivered the following key impacts, which improved clinical care for bipolar women in the UK:

4.1 New NICE guideline informing risk assessments and care plans for women at risk of postpartum psychosis

Cardiff research findings [3.1, 3.2, 3.6] on the prevalence and risk factors of postpartum psychosis were incorporated into the National Institute for Health and Care Excellence (NICE) 2014 Clinical Guideline CG192 entitled 'Antenatal and postnatal mental health: clinical management and service guidance'. A member of the Cardiff team, Jones, was part of the 2014 NICE guideline development group [5.1, p.6].

The guideline, designed to provide best practice for health, public health and social care practitioners in the UK, cited Cardiff's identification of the risk of postpartum psychosis in women with bipolar disorder [3.1] in section 2.3 [5.1, p.27-28]. The particular risk to women with type I bipolar disorder [3.2] was also cited in the introduction to the short version of the guideline, 'Recognising mental health problems in pregnancy and the postnatal period and referral' [5.2, p.6].

Cardiff research findings on the risks presented by family history, as well as the importance of monitoring for postpartum psychosis during the first two weeks after childbirth, were also reflected in recommendations included within the long and short guidelines, for example:

- In line with the Cardiff research [3.2, 3.6], the full guideline recommends that: "If a woman has any past or present severe mental illness or there is a **family history** of severe perinatal mental illness in a first-degree relative, be alert for possible symptoms of postpartum psychosis in the **first 2 weeks after childbirth**" [5.1, p.845].
- The short guideline also uses Cardiff evidence [3.6] in Recommendation 1.6.1, stating that: "Assessment and diagnosis of a suspected mental health problem in pregnancy and the postnatal period should include: [...] **family history** (first-degree relative) of mental health problems" [5.2, p.31-32].

4.2 Commitment of £365M for new specialist perinatal services in England

Following the publication of the NICE guideline, the Cardiff team was instrumental in supporting vital changes to clinical provision. This was achieved via joint working with a coalition of 100 maternal mental health charitable organisations (including Bipolar UK, Family Action, MIND, NSPCC and Samaritans), under the umbrella of the Maternal Mental Health Alliance (MMHA).

MMHA commenced a major lobbying campaign called '*Everyone's Business*', which focused on the critical need for new specialist perinatal mental health teams across England. Jones was Chair of the Campaign Development Group. MMHA incorporated Cardiff research findings on individual risk of postpartum psychosis into the campaign activity and, using data from an MMHA mapping exercise, demonstrated that, in 2015, less than 25% of England was covered by a specialist perinatal mental health service [5.3].

Emily Slater, Chief Executive of MMHA stated that the organisation "*always built our campaign for specialist services firmly on the experience of women backed by the evidence base that the research of Professor Jones and the Cardiff team has provided [...] Our campaign has been remarkably successful and has led to an unprecedented increase in funding [for perinatal mental health services]*" [5.3].

This funding increase occurred in 2016 when NHS England announced £365M for Perinatal Health Services, based on the MMHA campaign [5.4, p.5]. Independent Evaluators of the *Everyone's Business* campaign cited Cardiff research [3.1, 5.5, p.4] and noted that "Stakeholders interviewed for this evaluation, including senior clinicians, NHS England representatives and local commissioners, acknowledged that the Campaign activities had either fully, or significantly, contributed to these funding commitments" [5.5, p.12].

Following investment from NHS England over 80% (as opposed to 25%) of Care Commissioning Groups in England were able to deliver services meeting the NICE guidelines

outlined above [5.3], and between 2016-2021, 30,000 women in England were able to receive specialist mental health perinatal care, not previously available [5.4, p.5]. Emily Slater, Chief Executive of MMHA writes *“These services can now, based on the research from the Cardiff group, identify women at high risk of postpartum psychosis and provide them the care through pregnancy and following childbirth that they need. It is my strong belief that women are now alive who would have died prior to these developments”* [5.3].

4.3 Training for professionals

Dr Liz McDonald, Clinical Lead of the Royal College of Psychiatrists Perinatal Workforce Development Group, noted that Cardiff’s research (e.g., the particularly high risk of postpartum psychosis in women with bipolar type I [3.1] and the need for clinicians to take a full family history and explore prior mental health episodes [3.3-3.6]) is now *“key to the work of specialist perinatal psychiatrists and teams, allowing them to make plans with women based on their individual histories of illness, prior pregnancy history and treatment response”* [5.6].

McDonald also highlighted that, since 2016, increased funding into perinatal mental health (see Section 4.2) resulted in more clinicians taking up roles in this discipline, many of whom have not completed formal perinatal mental health placements [5.6]. Consequently, the Royal College of Psychiatrists implemented a £1.4M programme called *Building Capacity: Psychiatry Leadership in Perinatal Health Services* to train the Perinatal Workforce. This includes a 12-month intensive training programme for new consultant perinatal psychiatrists, as well as masterclasses and intensive courses for consultant psychiatrists and senior trainees. The training has been delivered to 480 psychiatrists to date and is firmly based on Cardiff’s research, with a specific focus on undertaking individual risk assessments for postpartum psychosis in bipolar women [5.6]. McDonald stated, *“it was clear that the work of the Cardiff group was important to ensure informed delivery of care by the developing perinatal mental health services and therefore needed to be a central part of the training courses we were developing”* [5.6]. She adds, *“As well as helping design the programme, Professor Jones has delivered training to participants including formal lectures, detailed review of papers and case-based discussion...Clinicians have commented on how important this work is to their practice and how it will influence their clinical practice”* [5.6].

Dr Jessica Heron, CEO of Action on Postpartum Psychosis also noted that her organisation worked closely with the Cardiff team to *“develop a training package in postpartum psychosis for health care professionals”*, focused on identifying women at high risk of developing postpartum psychosis. Since August 2017, 16 workforce training courses have been delivered to 300 UK professionals, including psychiatrists, midwives, health visitors, GPs, obstetricians, mental health nurses, psychologists, social workers, and Acute & Emergency staff [5.7]. Attendees reported that *“I feel much more equipped and knowledgeable...[in] how to identify, manage and support women and their families as well as signpost them to the right resources.”* [5.7].

In summary, Cardiff’s leading mental health expertise informed recommendations within a vital NICE clinical guideline designed to enhance perinatal mental health provision to women at high risk of postpartum psychosis. The research was also used to evidence the critical need for substantial investment in new specialist perinatal mental health services across England, and informed the development of enhanced training for clinicians and healthcare professionals. These changes, as noted by Emily Slater from MMHA [5.3], ensured that at risk bipolar women are now provided with targeted support reducing the likelihood of them experiencing severe mental health episodes during and after childbirth. Cardiff’s impact in this area can be further illustrated by their work on scripts for a postpartum psychosis storyline for the BBC soap opera, *Eastenders*. One episode was watched by 7 million viewers [5.8] resulting in a 400% increase in women contacting Action on Postpartum Psychosis [5.7].

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] NICE Guidance CG12 Antenatal and postnatal mental health: clinical management and service guidance CG192 (Full Guideline)

Impact case study (REF3)

[5.2] NICE Clinical Guideline Antenatal and postnatal mental health: clinical management and service guidance CG192 (Short Guideline)

[5.3] Testimonial: Emily Slater, CEO Maternal Mental Health Alliance

[5.4] Perinatal Mental Health Community Services Development Fund: Application Guidance, NHS England, 19 August 2016

[5.5] Everyone's Business Campaign Independent Evaluation Report, Maternal Mental Health Alliance, Summer 2016

[5.6] Testimonial: Liz McDonald, Clinical Lead, Perinatal Workforce Development, Royal College of Psychiatrists

[5.7] Testimonial: Dr Jessica Heron, CEO, Action on Postpartum Psychosis (APP)

[5.8] Lewis R et al, (2018) Qualitative exploration of the effect of a television soap opera storyline on women with experience of postpartum psychosis BJPsych Open 4, 75–82. DOI: 10.1192/bjo.2018.9