Review of Maternity Services – Health and Social Security Panel – February 2021

- 1. This submission is made in response to the Health and Social Security Scrutiny Panel request for input regarding the current maternity provision for women, their babies and partners provided by Jersey General Hospital ("JGH") and the relevant community providers within Jersey.
- 2. This paper focuses particularly on the Terms of Reference published on 8 February 2021, namely:
 - 2.1. Safety and effectiveness of care provided during the antenatal stages of pregnancy
 - 2.2. Appropriateness of current policies relating to maternity services and their application
 - 2.3. Ability for women to make safe and appropriate choices of maternity care for themselves and their babies
- 3. This paper specifically relates to JGH's current policy on the provision of Anti-D immunoglobulin to pregnant women with Rhesus Negative (A negative) blood type (c10% of the Jersey population). Currently, JGH and its clinicians do not follow recommended practice as detailed by the UK's National Institute of Clinical Excellence ("NICE") guidelines and the relevant professional guidance issued by the Royal College of Obstetricians and Gynaecologists and the Royal College of Physicians. As such, the affected women in Jersey do not receive standard, prophylactic antenatal care provided in both the UK and Guernsey as a matter of course. Further, the options open to women who are Rhesus Negative are not communicated in a consistent manner nor is the policy regarding treatment transparent, impacting upon both the woman's choice and the delivery of her antenatal care.
- 4. The author of this paper is currently under the care of the Maternity Services at JGH and is an experienced healthcare lawyer who has previously advised NHS maternity units on clinical governance and risk over a 20 year period in the UK.

Rhesus Disease

5. Rhesus disease occurs when a mother has rhesus negative blood (RhD negative) and the baby in her womb has rhesus positive blood (RhD positive). A mother must have also been previously sensitised to RhD positive blood.

- 6. Sensitisation happens when a woman with RhD negative blood is exposed to RhD positive blood, usually during a previous pregnancy with an RhD positive baby or when a bleed takes place during the current pregnancy. The woman's body responds to the RhD positive blood by producing antibodies (infection-fighting molecules) that recognise the foreign blood cells and destroy them.
- 7. If sensitisation occurs, the next time the woman is exposed to RhD positive blood, her body produces antibodies immediately. If she's pregnant with an RhD positive baby, the antibodies can cross the placenta, causing rhesus disease in the unborn baby. The antibodies can continue attacking the baby's red blood cells for a few months after birth.
- 8. Treatment for rhesus disease after delivery can include a light treatment called phototherapy, blood transfusions, and an injection of a solution of antibodies to prevent red blood cells being destroyed. If rhesus disease is left untreated, severe cases can lead to stillbirth. In other cases, it could lead to brain damage, learning difficulties, deafness and blindness.
- 9. About 10% of the population will have RhD negative blood based on UK data. Rhesus disease is now very rare in the UK given the use of prophylactic Anti-D immunoglobulin.

Background to Anti-D immunoglobulin request

- 10. The author is pregnant with her second pregnancy and her blood group is Rhesus negative. Her first delivery took place in London where she received Anti-D immunoglobulin in the pregnancy's third trimester and on a prophylactic basis as required by "NICE" guidelines.
- 11. At the first appointment with her community midwife in October 2020, she was informed that Anti-D immunoglobulin was not given as a matter of course in Jersey but could be purchased privately. At her subsequent appointment with her Obstetrician in November 2020, she was informed that the Haematology Department of JGH will not provide Anti-D immunoglobulin to Rhesus negative women on a routine basis and that it could not be purchased privately.
- 12. It is the author's understanding that the Haematology Department of JGH relies upon the following rationale regarding its current policy:
 - 12.1. the States of Jersey has not provided adequate funding for Anti-D immunoglobulin administration on a routine, prophylactic basis for women and,
 - 12.2. the Haematology Department will respond to evidence of bleeding antenatally and/or associated medical complications connected to Rhesus disease before taking active management of such women with Anti-D. The Haematology Department attempts to reassure pregnant women that the current policy ensures all who require Anti-D

immunoglobulin are "caught" by the process of reporting any accidental injuries or bleeds to their midwife/GP/obstetrician, or, by the antenatal review of maternal history to assess whether there are any unusual clinical risks relating to that particular mother which justify Anti-D immunoglobulin administration. The midwife/GP/obstetrician can then request the Anti-D immunoglobulin from the Haematology Department acting as a form a gatekeeper to the product.

- 13. In the author's view this places both the pregnant woman and the treating clinicians at unnecessary risk. The policy does not cater for the fact that a woman may not be aware that she has injured herself nor does it accommodate clinical evidence suggesting that bloods are transferred between mother and fetus in any event during the third trimester.
- 14. The author subsequently wrote to JGH expressing her concerns about the policy and highlighting the disparity between antenatal practice in the UK and Guernsey¹. After email correspondence with various clinicians and a meeting with the Haematology Department in January, she received a dose of Anti-D immunoglobulin in late January 2021. The Haematology Department considered her medical history justified the administration of the prophylactic dose, albeit it had been denied to her up to that point. It is understood that JGH is now reviewing the Anti-D immunoglobulin policy but the author has not been provided with a timescale for such a review. In the meantime, pregnant Rhesus negative women in Jersey may not provided with this standard treatment nor may they be aware that JGH does not provide standard, prophylactic care to protect their babies.

The current policy is a risk to women and their treating clinicians

- 15. The NHS website on Rhesus disease is clear (https://www.nhs.uk/conditions/rhesus-disease/prevention/):
 - 15.1. Rhesus disease can largely be prevented by having an injection of Anti-D immunoglobulin
 - 15.2. Anti-D immunoglobulin is also administered routinely during the third trimester of pregnancy if mother's blood type is Rhesus negative ("RhD negative"). This is because it is considered likely that small amounts of blood pass from mother to fetus during this time.
- 16. The NHS website reflects the relevant NICE guidance dating from 2008 but reviewed in 2015 (https://www.nice.org.uk/guidance/ta156/chapter/1-Guidance). At paragraph 2.5:
 - 16.1. It estimates that 10% of all UK births are RhD negative and without prophylactic anti-D immunoglobulin, 520 births per year would

 $^{1\,}$ The author contacted a practising Obstetrician in Guernsey who confirmed that Anti-D immunoglobulin is administered as a matter of course in Guernsey at 28 weeks as she wished to establish whether it was a question of economy of scale on a population basis which prevented the routine availability of the product for Jersey women.

- require close monitoring with 10-12% requiring intrauterine blood transfusions.
- 16.2. The author's obstetrician informed her that she was the fourth woman in her practice in the last 6 months who has asked about Anti-D immunoglobulin given their RhD negative status. The current JGH policy is unclear and causes confusion given that it is a mandatory requirement within the UK.
- 17. The clinicians treating RhD negative women are not following good practice and the recognised standard of care in this area as determined by their own professional bodies. Routine Anti-D immunoglobulin for RhD negative women is recommended by both the Royal College of Obstetricians and Gynaecologists ("RCOG") and the British Committee for Standards in Haematology ("BCSH"):
 - 17.1. The RCOG guidance of March 2011 (https://elearning.rcog.org.uk/sites/default/files/Early%20pregnancy%20loss%20-%20management/GTG22AntiD 1.pdf) suggests that 60% of pregnancies to RhD negative women are likely to have RhD positive babies and as such it is recommended that all RhD negative women receive anti-D immunoglobulin in their third trimester as standard practice (author's emphasis)
 - 17.2. The BSCH guidance produced in 2014 is also clear (https://onlinelibrary.wiley.com/doi/full/10.1111/tme.12091) and formed the basis of the NICE 2008 guidance previously referred to. All RhD negative women who do not have immune Anti-D, should be offered additional routine prophylaxis with Anti-D immunoglobulin during the third trimester of pregnancy (author's emphasis)
 - 17.3. The BSCH guidance describes how prior to the availability of Anti-D immunoglobulin, the incidence of rhesus disease in fetus and newborns was 16%. This sensitisation rate has now been reduced to the range of 0.17-0.28% achieved by the introduction of routine antenatal Anti-D prophylaxis during the third trimester of pregnancy.
- 18. The clinical evidence is clear and the mandatory requirement removes any risk introduced by clinical judgment calls as to whether a mother has been sensitised to Rhesus positive blood. JGH's current policy introduces risk unnecessarily and also causes anxiety in the expectant mother. Prior to receiving her treatment, the author was left with the possibilities of:
 - 18.1. leaving Jersey and her young family in the middle of the Covid pandemic to secure Anti-D immunoglobulin either the UK or Guernsey with the associated quarantine restrictions;
 - 18.2. suggestions from other mothers anecdotally that she should report a false bleed to the Antenatal Clinic to ensure access to the Anti-D immunoglobulin with the associated unnecessary, supplemental investigations that such a report would prompt.
- 19. Further, JGH clinical teams are exposing themselves to unnecessary liability risk: the mandatory nature of the relevant clinical guidance is likely to make

any future negligence claim arising from a mother or newborn's damage from Rhesus disease indefensible.

Access to Policies re: Maternity Care and informed choice by expectant mothers

- 20. The panel may not be aware of what information is available to expectant mothers regarding the care they will receive in Jersey. The Maternity Unit's website provides information to expectant mothers in the form of a drop down menu. It contains helpful guidance from issues ranging from scanning, community midwifery management, birth plans and common complications (https://www.gov.je/Health/PregnancvAndBirth/ScansAppointments/Pages /ScreeningDownsEdwardsPataus.aspx). It provides links to NHS sites suggesting that the Maternity Unit does follow UK practice guidance in relation to maternity services provision. It does not contain any information regarding Anti-D. This is in contrast with some UK units which provide leaflets information for Rhesus negative mothers (https://www.hev.nhs.uk/patient-leaflet/antenatal-prophylaxis-with-antid/) or copies of their clinical governance policy on the internet (https://www.royalberkshire.nhs.uk/Downloads/GPs/GP%20protocols%20 and%20guidelines/Maternity%20Guidelines%20and%20Policies/Antenatal /Anti%20d%20guideline V8.0 GL786 JUL20.pdf).
- 21. There are no details of JGH's Anti-D policy in the public domain; women are required to raise the issue with their midwife or doctors. Some women may not even be aware that they are Rhesus negative and certainly not familiar with the clinical recommendation of prophylactic treatment.
- 22. Women are only made aware of the limited Anti-D provision whilst in their second trimester when they meet their Obstetrician providing them with limited time to challenge the JGH policy or make alternative arrangements to source the Anti-D immunoglobulin whilst they are pregnant. There is undoubted confusion about how access to Anti-D immunoglobulin amongst community providers with both GPs and community midwives aware that access was not automatic but unclear as to how women could actually obtain Anti-D immunoglobulin. The author relied on her professional knowledge and experience to obtain the treatment. This does not amount to "informed choice" and can increase anxiety unnecessarily for the pregnant woman.

Conclusion

- 23. The Health and Social Security Panel has an opportunity to ensure that women in Jersey receive the same standard of antenatal care as they would receive in the UK and Guernsey.
- 24. It is suggested that the provision of Anti-D immunoglobulin is not a matter of clinical discretion; the NICE guidance and Royal College guidance is clear that

provision of Anti-D immunoglobulin to RhD negative women is mandatory as a prophylactic measure at 28 weeks. Pregnant women in Jersey should not have to lobby their clinical professionals for access to treatment considered a recognised necessity in the UK and Guernsey. Further, the clinical professionals risk censure in any future related litigation. Should they be referred to their professional regulator, the General Medical Council (GMC), their practice will be assessed against the standards of UK practice. The author awaits the outcome of both JGH's internal review of the Anti-D immunoglobulin policy and the Panel's timely review of Maternity Services in the hope that current practice will change and reflect UK practice.

- 25. It is suggested that any future policy on Anti-D immunoglobulin should be placed in the public domain so RhD negative women and those who treat them at all stages of their antenatal care are aware of the JGH policy.
- 26. The author is happy to expand upon any of the above points for the Panel should it wish.

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