

Maternity & Neonatal Services

-Summary of Feedback shared on Care Opinion

August 2020- April 2021

BRIEFING PAPER

The purpose of this briefing paper is to demonstrate how the current database in Care Opinion can be used to inform the Health Population Needs assessment for Maternity & Neonatal services. The following information reflects the stories published on Care Opinion up to 20th April 2021 in relation to maternity & neonatal services across Health and Social Care Northern Ireland.

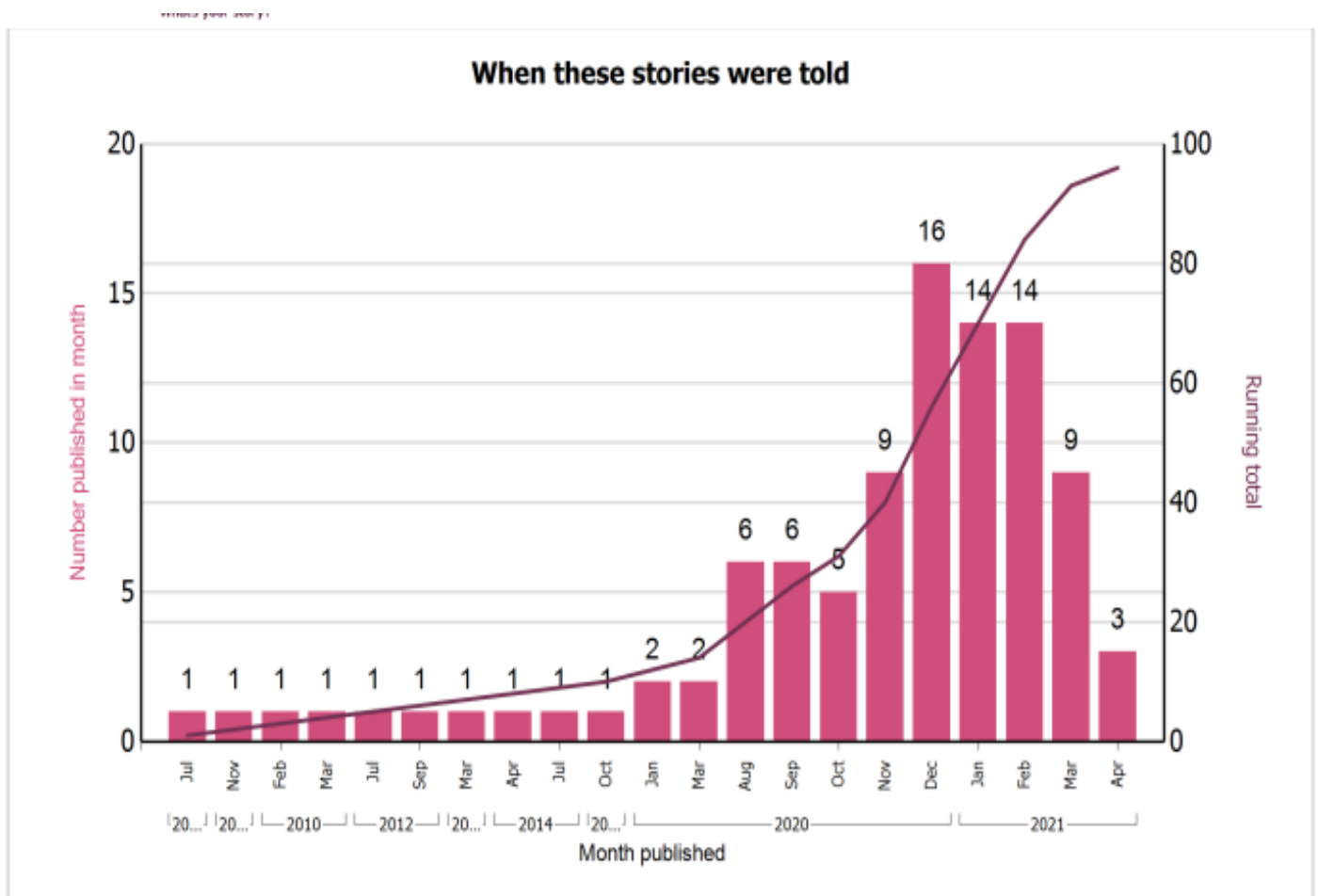
1.0 CONTEXT

Care Opinion launched in NI on 3rd August 2020 as a new opportunity for service users, relatives and carers to share feedback on their experiences of HSCNI. It is an online user feedback system which allows for feedback loop between the service and the author of the story. The purpose is to effect change at a local level and also ensure the voice of service user experience influences and impacts upon strategic direction and decisions.

2.0 OVERVIEW

In total there are **96** stories shared on the system which relate to Maternity and Neonatal services (85 maternity and 11 neonatal). Chart 1 demonstrates how the number of returns in maternity and neonatal has increased over the period of time since the launch of Care Opinion and also highlights a small number of stories (n=9) which are legacy stories which were in the system prior to the launch of Care Opinion in NI.

Chart 1: Number of stories submitted each month on Care Opinion



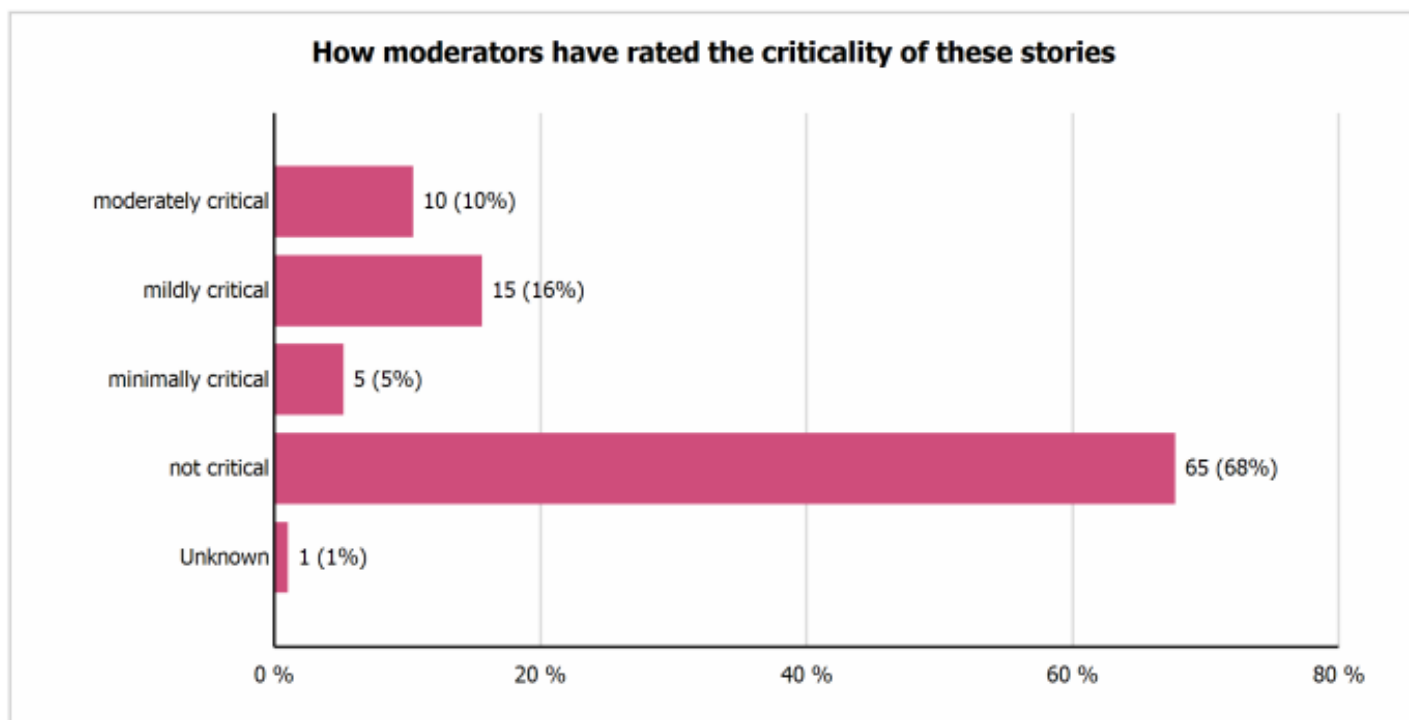
Authors are asked to identify if they are a service user, parent, relative etc. The following table shows to date the majority of stories have been submitted from the perspective of the service user.

Table 1. Which term best describes you?

Term	Number	Percentage (corrected to closest whole denominator)
Service User	84	87
Parent/Guardian	7	7
Relative	5	5

As part of the analysis through Care Opinion, each story is assigned a criticality score by a moderator to highlight the level of critique included in story. Chart 2 illustrates the scores for the 96 stories submitted. Table 2 outlines the definition of each score

Chart 2. Criticality rating of stories submitted on Care Opinion relating to Maternity and Neonatal Services across Northern Ireland



NB: criticality scores are assigned by moderators (not the public) to stories to support our alerting service. They are assigned *per story* not *per service*, so may reflect criticism of services other than your own. We provide them here purely for information, with these caveats in mind.

Table 2. Definition of Criticality scores as assigned by Care Opinion moderators

Score	Definition
0	No Critical Content : Entirely positive or neutral postings with no hint of criticality.
1	Minimally Critical: Mention of dissatisfaction with non-clinical non-personal aspects of care, typically “facilities” issues such as food, parking, or waiting.
2	Mildly Critical: More specific but still mild criticism, which may also include non-clinical but interpersonal issues such as attitude of staff, compassion, politeness. This might include the timely nature of the service whether in hospital or in the community where it has caused distress, e.g. carers not turning up on time
3	Moderately Critical: Criticism which may include alleged shortcomings in clinical or non clinical aspects of care, the author may not say what the effect of these are. Also includes serious comments about facilities: ‘never cleaned’; and where people’s essential basic care needs are not being met, e.g. inadequate nutrition and hydration, development of bedsores
4	Strongly Critical: Serious criticisms of specific unnamed staff or groups of staff, or of clinical or other care or facilities. This might have had very serious consequences for physical or emotional health. These will be described by the author. There might also have been social consequences that have increased the risk or vulnerability of an individual
5	Severely Critical: Posting alleges or describes actions or events which may be illegal, grossly negligent, or allege serious misconduct by named members of staff or organisations.

Care Opinion is built upon the concept of “Tell us your story” and supports the author to highlight what matters to them in their experience (see Section 3.0); however there are three closing questions included on the platform exploring what went well, what needs to improve and the feeling and emotion related to the experience. This is detailed in Table 3 and further illustrated in the word clouds in the Appendix 1.

Table 3. Tags indexed by the authors of the story in response to the three closing questions.

Most common tags added by authors to these stories					
<i>What's good?</i>		<i>What could be improved?</i>	<i>Feelings</i>		
staff	31	communication	5	thank you	37
Care	27	staff attitude	4	grateful	18
midwives	27	support	4	safe	17
above and beyond	12	help	3	fantastic	13
support	11	response to buzzer	3	amazing	11
friendly	10	aftercare	2	at ease	11
reassuring	10	dismissive	2	cared for	11
compassion	8	food	2	supported	11
doctors	8	induction	2	helped	10
explanations	8	monitoring	2	positive	8
		not being listened to	2		
		Should listen	2		
		very bad	2		
		waiting area	2		

3.0 Thematic Analysis of Narrative

Framing each story with the lens of “What matters to you” the following themes have been identified in the narrative. The values of HSC and standards for Patient Client Experience are also echoed in the themes. Each theme is illustrated using quotes directly from the story to ensure the voices of the stories are heard. Names have been included in the quotes however consideration should be given to anonymising the quotes if included in public facing document. They encompass both the positive experiences where this was part of the experience and also the negative impact when the theme was not part of the experience. It is also important to highlight that the themes are not mutually exclusive and a number of themes can be identified within the quotes. There are also reflections included on the interface of services such as maternity and Emergency Departments.

3.1 MATERNITY SERVICES

Compassionate Care

“...Rachel kept me focused for the whole experience, spoke in a calm, low voice and made me believe in myself, when the going was getting particularly tough. The staff are a credit to the hospital, their profession, and the NHS as a whole. They are the embodiment of compassionate care. I will be forever grateful to them. Thank you so much...”

“...Personal thanks to Jacqui too who sat with me to help me with the breastfeeding struggle I had at the start and restored the confidence I needed to keep going with it. And another extra note of thanks to Joanne for coming up the next morning to see my daughter again. That simple act alone makes you feel like you are more than a number passing through their doors...”

“...In particular, I'd like to really praise the health care assistant. She was wonderful. I suffer from white coat hypertension and became very anxious when I entered the room and had my initial monitoring of my blood pressure (which was high!). The health care assistant was amazing at calming me down. She was so kind and informative. She helped me to take some deep breaths and relax/close my eyes...”

“...on a particular occasion when there was no answer to the buzzer she was left to try and get out of bed to lift our daughter and feed her herself. A care assistant who was on duty done nothing, only downgrade how my wife was doing things. Telling her she was holding her wrong, holding her in a way that she would choke. Giving out how her baby grow was damp and how she was too cold. I found it very disheartening that a member of staff would go on like this especially considering the circumstances, and to receive that sort of treatment is just not the way it ought to be...”

Person centred values – Listening

“...I really appreciated how the midwives in the delivery suite listened to my birth preferences and supported me by bringing the props to the room that I wished to use in labour such as a birth ball, rocking chair and mat...”

“...There was one moment after the staff handover that a consultant came into the room - and I felt really unseen as he discussed my care with the midwife loudly and in front of me without directing conversation at me or involving me in the discussion which I didn't really appreciate, as I felt strongly that this was my labour and my baby and I thought that the care should be more person centred than this....”

“...This midwife was uninterested at best and made me feel very vulnerable and alone. Due to failure to progress I was taken to the labour ward where I was met by another midwife who barely spoke to us and gave me the impression that they were not very happy to see us. I cannot remember receiving any encouraging or comforting words from anybody. I ended up having an emergency cesarean and one of the worst things I can remember was not the medical procedures happening to me but the consultant shouting across the room telling someone not to bother calling another consultant in for an emergency she would be done in 10 mins. I felt like a slab of meat on the table and was overcome with anxiety about my cesarian being rushed...”

Recognition of the role of father/partner during labour

"...They made myself and my partner feel very safe and comfortable. It was a nervous time as this was our first baby. A big thank you to all the staff in delivery and up in the maternity ward.."

"...Barbara was with us throughout labour, including during the induction process which was quite daunting as my husband wasn't able to be there at that point due to the current restrictions. She provided great support to us and put us at ease – she is fantastic at her job...."

"...I had a slightly difficult induction with it lasting two days before going into labour due to issues with my baby's heartbeat. In normal times this alone would have been difficult enough but during a pandemic without my husband being allowed in was hard going... the midwives were excellent and consoled me when I was distressed..."

"...I had a long induction and each midwife (all 4 due to shift change) were incredible. They ensured I was comfortable, kept on top of pain relief and ensured my husband was comfortable as it was a long labour..."

High standard of care

"...I just want to thank all the midwives involved- particularly Chrissie, Laura and Grace who I felt delivered the highest standard of care and attention from the minute I met them. We were really impressed with the entire running of the delivery suite department and felt we were really well supported every step of the way..."

"...gratitude to the staff in both the assessment unit (student midwife Paula), and the Midwifery Led Unit (Sister Louis and team) for the very swift delivery of our daughter shortly after our arrival to the hospital on the 26th January. You all jumped into action and your care and attention was second to none and a shining example of what Midwifery led care should be, completely person centred and supportive. We were back home within a few hours. Thank you for making our Journey such a positive experience..."

"...After my first loss, I received a phone call from a receptionist to confirm a date and time for a 12 week scan I no longer needed. I had to explain that I lost the pregnancy. She thanked me for letting her know. I came off the phone and sobbed. A simple link between my record at A and E and maternity booking could have prevented this further little trauma. A simple leaflet given at A and E explaining what happens now, where to go for further blood tests could have prevented that further tiny trauma... I know that such losses happen and staff deal with them regularly. But when a woman is suffering a miscarriage her world is being up-ended and a whole imagined future is slipping from her, physically, emotionally and spiritually. It's not just another Wednesday. It's the Wednesday everything changed. Please. Please do something to rectify the lack of support following miscarriage..." [This story relates to the experience of attending the Emergency Department due to a miscarriage.

"...C section, parted from partner after a couple hours before moved to recovery ward, high amount of blood loss, then having to look after a baby whilst not being able to move my legs properly. Laying in my blood soaked sheets that didnt get changed till a new midwife came on the ward. Given a sponge bath with the catheter bag being left on the floor and it nearly being stood on..."

"...I was treated with care, respect and support right from my first appointment and my husband also commented on the high standard that he witnessed at the appointments he joined me in. All the staff were excellent and the midwives involved in my babies care the day he was born went above and beyond for us both..."

Empathetic response to difficult or emergency situations

"...Once on the postnatal ward and prior to discharge my baby was checked by the paediatric team. An issue arose and the paediatric team were very professional, putting myself at ease and ensuring follow up was prompt..."

"...The care my wife received was brilliant. After our daughter was born and we were back to the ward, following my wife having to go to theatre for treatment for a 3rd degree tear it was noticed she had lost a lot of blood and they transferred her to the ward to get a blood transfusion. She was very weak and needed a lot of help. The midwives were excellent..."

"...There was no specific place I could sit in A and E while I went through contraction pain. No way I could hide my face as I publicly endured pain in front of faces, some of whom I knew, as I went through this huge personal loss. I had to repeat the same information to 3 Dr's and as many nurses. Choking back the tears each time. And failing to. The care I received, physically, was superb. Second to none. But this was because this miscarriage went badly and I needed intervention..." [This story relates to the experience of attending the Emergency Department due to a miscarriage]

"...I am 8 weeks pregnant and was bleeding was told by out of hours gp to go to a&e. I went to the ulster to be told I can't come into the building due to covid. Was send out to the carpark in the dark, alone and bleeding with a number to call for obs and gynae. Stood waiting for them to call me back to tell me they cannot see me and I will have to wait to be seen at early pregnancy unit 5 days later..."

"...A little under 8 weeks ago I suffered a placental abruption 30 weeks into my pregnancy, unfortunately our baby boy Flynn didn't survive and I barely made it through myself as I had a huge clot and lost a lot of blood. If it wasn't for the care and love I received from the midwives at the Ulster Hospital I don't think I would be here today. Especially Cathy who kept me smiling and made me laugh but held my hand when I needed to cry and helped me through the hardest day of life..."

Empowerment & Choice

"...They recommended trying ABC ward (active birth centre) to give birth in a pool which was free that day. So I went around to ABC ward and within the hour gave birth to my son! Best birthing experience I've had by far, with very little medical intervention which was how I wanted..."

"...Dr McCabe fully supported my decision to try for a natural birth and provided me with current evidence in order to make an informed choice. She treated me with utmost respect and dignity, listened to my woes and reassured my wobbles. She went above and beyond to treat me as an individual, my case definately did not fall neatly into any hospital protocol. Her experience and empathy were evident and I felt safe and empowered..."

"...The Dr's were brilliant and put me and my husband at ease. I was unsure if I could tell when to push with having the epidural, but Cathy guided me with every push - for which I'm eternally grateful. It wasn't until after my twin boys were delivered that I found out it was Maireads first twin delivery..."

"...I had visited ABC unit during pregnancy & verbally requested this if possible on arrival, as well as having detailed written preference for birthing there in my notes (which sadly I believe to have been ignored). Was left for several hours at the end of the non labour ward, briefly greeted by different midwives on a handful of occasions & offered oral pain relief..."

Efficient and effective service

"...For the last few months now the waiting times at maternity appointments have been shocking. My partner has had to wait +1 hour at least each time whilst trying to keep a full bladder. I don't understand how the appointments run so far behind, there is clearly a staffing problem that needs to be addressed..."

Importance of access to mental health services or peer support

“The mental health team were equally abysmal. I was seen by someone who told me they didn't really know much about postnatal depression but saw fit to discharge me saying it would be better for me as otherwise I would have social services involved for a year. I cannot express how this all made me feel when I was going through a mental health crisis and I was completely let down by every health care professional I met....”

“...Now I have a 5 week old son, and feel like I'm mentally struggling due to not having face to face support from mum groups, or anyone that can help me. Only given helplines to ring, everywhere's closed...”

3.2 NEONATAL SERVICES

Staying informed

“...I was very happy when my daughter got transferred back here, the care she received in the unit was exceptional and I was kept very informed of everything that was going on. I will be forever grateful to all members of the team for making a hard experience that little bit easier...”

“...Our girl stayed in the unit for two full weeks and the care she received and us as parents was out off this world. We were allowed to visit her regularly when we wanted and the team were always lovely and on hand to give updates. Even at night when I was back on the ward the team were happy for me to phone down to make sure she was ok and this continued every night until we got her home...”

“The care in Craigavon was excellent. And we were made to feel very welcome. The staff were all very informative and friendly. One of the staff members was called Donal in the neonatal ward he was brilliant he made you always feel calm and at ease.. he was very helpful and good at explaining what was happening and keen to tell you how our baby was getting on...”

Recognising the importance of the whole family

“...I also received some little colouring books in the unit for my older daughter, I thought these were very good as they helped her to understand baby's journey in neonatal...”

“...Then at 17 days old, had to go to A&E due to him being sick and being admitted to the childrens ward for 4 days, alone with me again, crying because my baby was screaming, resting heartrate at 230, red skin, low oxygen, 39 temp, stopped feeding and had to go on a feeding tube, getting a canular for antibiotics, constant blood test and a lumbar puncture. Dealing with that alone, with 0 sleep and in pain from surgery and having to sleep on an armchair in hospital. Crying to the nurses, feeling depressed and like I was failing when in reality, I'd spent half of his life alone with him in hospital and not being able to get a cuddle from my partner or mum...”

“...The team of nurses took their team to know about my baby's older siblings and always made off them when they were allowed in at the weekend. Our children found it hard with their little sister in hospital and when they did visit the nurses made off them...”

Compassionate Care

“...She was taken soon after birth to the NICU where she remained for the next three weeks. All the time she was there we never worried that she wasn't getting the best care as ALL the staff were incredible and took time to explain everything to us and answer all our questions. They showed her love and compassion and made us feel that she was safe even when we weren't with her. Sadly she didn't get any better and she passed away at three weeks old but the staff helped make the worst day of our lives into one filled with happy memories and moments we will always

cherish. They supported us when we were at our weakest and we'll forever be grateful for all the efforts they made to help Maisie, even though for her it wasn't meant to be..."

"...Such special people who cared so diligently for my baby who arrived at 34 weeks. Without their knowledge, care and love I would not have my baby home with me. I can not thank them enough..."

"...The nurses and health care assistants treated her and the other babies like they were their own, reading them stories, dressing them, and with one particular nurse even playing nursery rhymes to the babies at night time. These may seem insignificant, but when you have to leave your own baby every evening in someone else's hands, it helps to know they are being treated with care and dignity, which I always felt there. I rang during the night every night to check on how she was doing, and not once did I ever feel like a nuisance or anything..."

Support and reassurance for the family

"...She [daughter] was taken to Craigavon neonatal unit as there was no room for her at Antrim. I felt worried & upset as I stayed in Antrim and she was in Craigavon as it is over an hour car journey for us...On our first day visiting our baby girl, we were greeted with friendly staff who instantly made us feel at ease. They made sure I was comfortable and explained to us clearly what our baby was being monitored for. The girls helped me learn to feed & change nappies & I feel so confident now..."

"... We had a few set back over the two weeks and the team talked us through everything and always made feel so much better. One nurse in particular was even happy to sit with me and show me how to express milk for my baby which I found hard..."


4.0 NEXT STEPS

Care Opinion is currently available across the system of HSCNI and will continue to support feedback on maternity and neonatal services. This briefing paper reflects the current feedback available to inform and influence strategic work. Going forward consideration should be given to the benefits of specific campaigning within these services to generate stories in this area and support local and regional learning.

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