healthwatch
Isle of Wight

Healthwatch Isle of Wight Maternity Services Report 2014

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1 Acknowledgements

Healthwatch Isle of Wight would like to express its thanks to everyone who contributed or supplied information for this piece of work on maternity services.

- Sara Ellis, Outreach and Engagement Officer for Healthwatch Isle of Wight would like to express very sincere gratitude to all the Island's Children's Centres for making her so welcome during this piece of outreach and for facilitating their service users to have tell their stories.

- Special thanks to Rachel Price at Ryde Children's Centre for promoting the work of Healthwatch and to Paula Cooley and team at Ventnor Children's Centre who helped guide the method of outreach undertaken.

- Thanks also to the numerous independent Parent and Toddler groups where outreach was undertaken. Finally huge thanks to the mothers themselves for frankly and honestly sharing their experiences and thoughts about how services could be improved.

- Many thanks to Boots Isle of Wight, Precious Cargo in Ryde Isle of Wight and the Isle of Wight Sling Library for donating the maternity survey prizes.

Healthwatch Isle of Wight looks forward to working positively with all the above and other partners in achieving the progress recommended in this report.

2 Introduction

Work-plan priority: Listening to and safeguarding children – our community engagement team will be talking to parents / carers and community groups to understand what the issues are – particularly around ante-natal and post – natal services

Healthwatch Isle of Wight is an independent local 'watchdog' and signposting service that works with decision-makers and service providers to help improve health and social care services on the Island. It was formed in April 2013.

Healthwatch I.W. keeps track of feedback from members of the public about NHS funded services and social care for people of all ages. We speak and listen to a wide range of people to get a broad picture of local experiences.

The Community Engagement aspect of Healthwatch was swift to build upon existing positive contacts and a range of outreach sessions in variety of venues were arranged. During May a general outreach session was held at a Children's Centre, the aim of this session was to raise awareness of what Healthwatch was and how people could become involved. It was a relatively small group of new parents and the conversation with them was very general and involved all present. Through an initial disclosure by a parent of a very poor birth experience , other parents joined in, with one saying that ' I never thought about how bad it was until I reflected on it afterwards'. Another said 'When I read the Staffordshire hospital report I could not believe that patients were drinking from flower vases, but my own experience meant if my husband had not brought me drinks it would have been the same for me' .

During July Healthwatch Isle of Wight held a work plan prioritisation day where over 40 organisations and individuals attended to look at existing trends in feedback and other issues to decide what priorities Healthwatch Isle of Wight should adopt for its first year. Following this event a public on-line poll was held to determine the final priorities. Safeguarding, listening to children particularly with regards to ante-natal and post natal care were designated as a priority.

A note about outreach and confidentiality: Unless the women telling their story indicated that they would like further contact with Healthwatch and the outcomes of the maternity report, no contact details were taken. Their stories are completely anonymous. In instances where the respondents did wish to complain they were signposted or referred to the appropriate services, but in general the women taking part shared their experiences with the aim of improving services in the future.

Throughout this report every necessary steps have been taken to ensure that stories remain anonymous but we accept that on occasion it may be possible to identify individuals. We would therefore ask that readers of this report respect the privacy of those who have shared their stories.

3 Methodology

A community engagement approach was adopted for this work-plan theme as it is recognised as an empowering method to give service users a voice in how services are shaped and delivered. The Outreach and Engagement Officer joined existing sessions over a 5 month period chatting to parents, joining in activities with them and their children, aiming to visit settings on more than one occasion where possible to build relationships.

Popay J., 2006, defines Community Engagement as the process of getting communities involved in decisions that affect them. This includes the planning, development and management of services, as well as activities which aim to improve health or reduce health inequalities.[1]

Healthwatch Isle of Wight utilised the principles outlined in the National Institute of Clinical Excellence (NICE) Public Health Guidance PH9 (2008) [2] are utilised throughout this piece of work. Key points of this include:

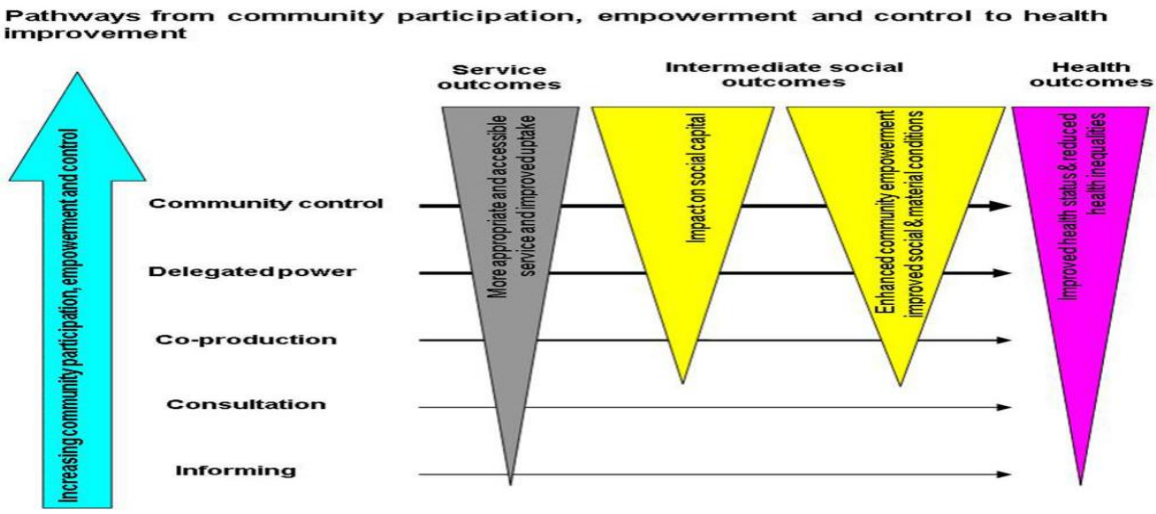
- 'utilise local people's experiential knowledge to design or improve services, leading to more appropriate, effective, cost-effective and sustainable services' and to' build more trust in government bodies by improving accountability and democratic renewal'...
- 'contribute to developing and sustaining social capital'

NICE defines Community development as being:

'about building active and sustainable communities based on social justice, mutual respect, participation, equality, learning and cooperation. It involves changing power structures to remove the barriers that prevent people from participating in the issues that affect their lives'.[2]

This is vital to the successful operation of Healthwatch Isle of Wight.

Figure 1 - National Institute of Clinical Excellence (NICE) Public Health Guidance PH9 (2008):



4 Executive Summary

The state of Maternity Services (Royal College of Midwives) 2013 reports that the number of births in England was 694,241 births in 2012, the highest number since 1971. [3] On the Island there were 1321 births in 2011 [4] and 1298 births in 2013 (figures provided by Isle of Wight NHS Trust).

The report further notes that incidences of obesity have more than doubled from 7.6% in 1989 to 15.6% in 2007 this means extra women requiring more specialist bariatric care. Feedback from obese mothers on the Island indicated that sometimes that care was not forthcoming with one mother citing a wrongly sited epidural, and others with gestational diabetes not having their dietary needs met whilst in hospital.

The 2007 Foresight Report projects obesity as increasing substantially in the coming years this means that the demand for extra care will increase. [5]

The State of Maternity Services report notes that nationally there is a shortfall of 4,800 midwives. Figures published by BBC Panorama programme in 2011 revealed that the ratio of midwives on the Island was 29.71; the highest ratio was 43.88 Middlesex University Hospital. [6] The Island is unique in providing a full maternity service, given the Isle of Wight birth rate, other areas would not be able to sustain the service. There are currently 42 FTE midwives practicing on the Island with an average age of 50. There are a number of midwives approaching retirement/recently retired which has led to some staff turnover.

There were 36 Healthwatch Isle of Wight outreach sessions across the Island from October 2013 – March 2014 in Children's Centres, independent parent and toddler groups and other groups where more vulnerable parents meet. There were approximately 200 pieces of feedback recorded from parents during these outreach sessions and some key themes emerged. Whilst on the whole mothers were happy with the care they received, there was a lot of acknowledgement that the 'midwives were rushed off their feet'. Some parents did not feel they had received the care they needed and shared very negative experiences. Mothers of second or further babies reported very little support to establish breastfeeding, together with mothers of first babies who did not receive the support that they needed especially post-natally, sometimes ending with them giving up trying to breastfeed.

Another common theme that emerged was the lack of diagnosis of babies who were tongue tied, together with treatment for this condition, it was common to hear that mothers had sought private services to get this resolved at their own expense.

In addition to the outreach programme, Healthwatch Isle of Wight also developed and distributed a survey, this was hand delivered to many of the settings previously visited, also publicised by social media and conventional press. Local businesses contributed goods to make up a hamper of baby products for which a prize draw of respondents was held.

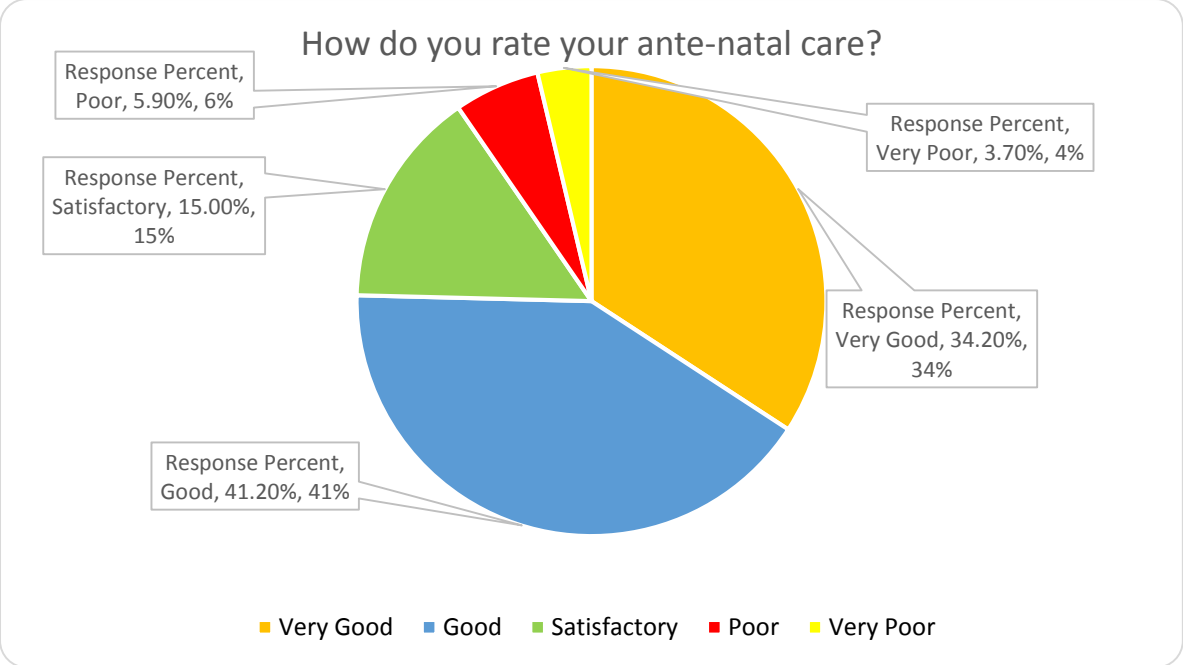
A total of 187 survey forms were returned. There were 17 questions relating to ante-natal, intra-partum, post natal care, feeding support (including breast and bottle feeding) and access to other maternity related services. Respondents were asked for comments on each question on an optional basis. The full data set from the responses is included in Appendix 2.

The Healthwatch Outreach and Engagement Officer also met with the Clinical Commissioning Group Commissioner for Community Services, the Head of Midwifery and a Supervisor of Midwives to discuss findings and to learn more about current practice and improvements planned by the department.

5 Ante-Natal Care

Figure 2

Responses received through the Healthwatch Isle of Wight Maternity Survey



The majority of mothers we spoke to and who completed our survey received good or very good care throughout the ante-natal period. Highlights of this were ante-natal classes held at Children's Centres that gave women the chance to make friends with other pregnant women.

This is good practice and very aligned with both NICE CG 62 Antenatal Care [7]and the Healthy Child Programme.[8]

However, a minority did not. Some were unclear what to pack when being admitted to hospital for the birth, some clarification or a simple list if not already in existence would be useful.

We were told that expectant mothers in the West Wight were invited to attend ante-natal classes at Cowes Childrens Centre, there being no provision at West Wight. Concerns were expressed by staff that it was unlikely that parents would engage in Childrens Centres if they had not previously attended antenatal classes, obviously the distance from the West Wight to Cowes would dissuade some from attending.

Mothers' experiences were varied, but there was a focus on not being able to get to know or build a rapport with Community midwives, which meant that they had to tell 'their story' several times with each change over and when their midwife was absent, this led to a lack of rapport and trust.

'I haven't seen my own midwife since booking appointment; feel very rushed by the other midwife'

This left mothers unsure of what to do if they had health worries or how to plan their birth effectively. There would appear to be two reasons for this; one is the rotation of midwives from the community and the ward, the second being where midwives worked as a team, mothers could see any one of the team, with some mothers saying they had seen 4 midwives throughout the course of their pregnancy.

Best Practice Guidance from the Healthy Child Programme advises 'giving women a single, named midwife who will oversee their care during pregnancy and after they have had their baby.[8] NICE CG 62 Antenatal Care advises continuity of care, and that antenatal care should be provided by a small group of health professionals with whom the women feel comfortable with. There should be continuity of care throughout the antenatal period.[7]

Second time mothers also noted the 'light touch' of the midwives and how they saw them infrequently to previous pregnancies, this did not appear to be a problem unless the mother was anxious or had health issues. Some mothers commented that this 'light touch' meant that they could not adequately plan their birth as they did not know the options available to them.

Several women told us that they had included the use of the birthing pool in their birth plan, when this was out of use due to refurbishment they were not aware and consequently disappointed. One said they 'had to fight to get a temporary one'

On the whole from our feedback, those women who had what they termed a 'complicated' pregnancy tended to report more highly of the quality of care they had received.

'Absolutely fantastic, professional, encouraging and an absolute credit to our maternity department'

Of concern were comments made to us that women were not routinely screened for Domestic Abuse.

Best Practice Guidance cited in the Healthy Child Programme states that it is important to explore parents feelings, attitudes and expectations towards pregnancy birth and the growing relationship with baby.[8]

NICE CG 62 Antenatal Care 1.1.1.5 and 1.5.5 advises that Health Professionals should offer women the opportunity to discuss issues including Domestic Violence. [7]

Further the 'Saving Mothers Lives' 2006-08 CMACE report continues to recommend 'Asking the question' about domestic abuse at booking or another opportune moment, with midwives having the discretion when to ask this depending on how the relationship is building. It also notes that women should be seen at least once on their own during the antenatal period to facilitate the disclosure of domestic abuse.[9]

There were also instances of first time mothers saying that staff did not take notice of what they were saying, or dismissed queries and of how they were feeling, which left them feeling both demoralised and confused.

There were also concerns raised of midwives not returning calls, another stated that blood test results were given over the phone in a very casual manner despite it being worrying news regarding risk of a Downs Syndrome baby.

> ' Midwife always seemed a bit distracted, very nonchalant, as though second pregnancies don't warrant a smile or a bit of 'TLC'. One appointment was so rushed that she failed to find fetal heart beat and sent me to maternity ward in a panic...'

IVF

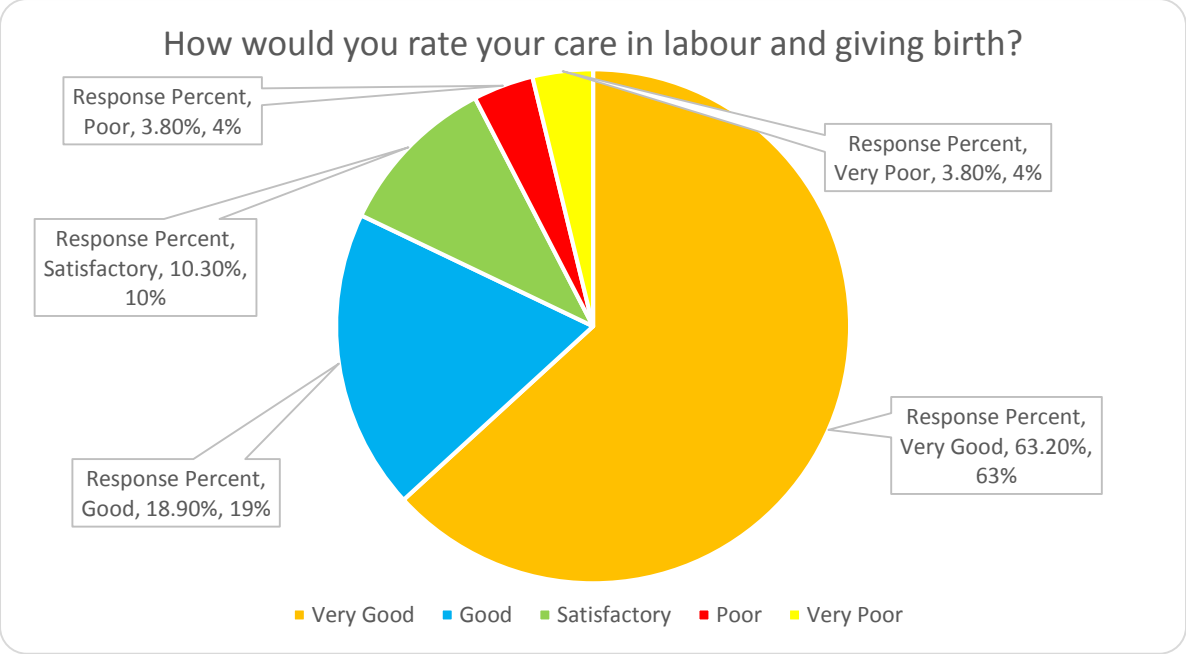
All comments received from women undergoing IVF were positive, including all aspects of the service. Staff were named as providing outstanding care;

> '...all very reassuring and never found me neurotic.'

6 Care During Labour and Birth

Figure 3

Responses received through the Healthwatch Isle of Wight Maternity Survey



The majority of those who took part in our survey rated the care they received as good or very good. Respondents frequently used words such as 'fantastic' 'amazing' 'calming' and 'knowledgeable'. These remarks referred to both midwife and consultant care.

There were several comments relating to the extra support offered by student midwives who often stayed beyond their shift to provide consistent care for women.

'The ward was packed and we had a room on maternity for the entire time we were there (about 11 hours) She stayed calm and left the chaos at the door. Was the best day of my life'

'All the midwives and nurses were brilliant. Doctor who assisted my delivery had no compassion or empathy and referred to my husband rather than me.'

Several women noted that whilst they received excellent care, this was because the labour department was quiet at the time of their giving birth.

Another said;

'Although maternity was really busy, all was well explained and all staff introduced themselves, a really good experience'

Another reported that she had been seen by 6 midwives in the space of 7 hours, she said that they were all really friendly, but that it wasn't good for continuity of care.

The care for women undergoing caesarean section was particularly highlighted as good. The use of student midwives who were dedicated to just one labouring woman was highlighted as providing reassurance and support. Some student midwives stayed after their shift to remain with the woman until after the birth which was appreciated, continuity of care being a vital aspect for some women.

However, for some hospital births, feedback from people we spoke with was a very mixed picture. Some women thought that they were having concerns and wishes dismissed, this centred particularly around labour accelerating and not being believed or examined to clarify the stage of labour.

'I feel I wasn't treated with any respect by the staff in the labour ward, they were rude and they did not listen to the concerns I was expressing to them that I was having about my labour'

One woman said although she had been adamant that she did not want pethidine, the midwife prepared an injection anyway.

Just over 10% rated care as satisfactory. Nearly 10% however, rated their care as poor or very poor. Frequently, the reason for this would appear to be from women who had their births induced, or for having long, slowly progressing labours.

Generally the women we spoke to who had been induced were unhappy with their experience, they talked about long waits, being sent home as there was not capacity to induce them on a certain day and having to rearrange childcare for other children. They also felt that once labour had started they were not examined to confirm this and were dismissed as not in labour.

One woman felt that she had been induced against her wishes (membrane sweep) and did not understand why as this was on her due date and she had no health issues. Another said a Locum consultant was angry that she had been induced as there were not enough staff to cope with the subsequent labour. However, one woman reported a very positive experience of being induced with good care throughout.

'Midwife provided fantastic support, couldn't fault experience, all very reassuring'

Another parent admitted due to premature labour was told by a midwife that if she had her baby on the Island it would die which she found extremely distressing. These views need to be balanced against other more positive views;

'Birth went exactly how I wanted with good follow up'

We spoke to some women who had given birth more than a year ago and were now planning pregnancy again, a significant minority of these were fearful of returning to St Marys because of previous traumatic experiences. It is important to note that the

worst experiences relayed to us were from women who had given birth more than a year ago, Practices such as making women assume a particular position during labour no longer happen, however reassurance needs to be given to these women to help them overcome their fears and enjoy the birth of their next baby.

Whilst there is conflicting advice on whether women should receive a 'debriefing' on their labour experience women that we spoke to said;

'A debrief after labour was useful'

NICE CG 37 Postnatal Care recommends giving women the opportunity to talk through their experiences and ask questions about the care they received during labour.[10]

This opportunity whilst recommended for women in the immediate postnatal period would be useful to those women who had previously had an upsetting birth experience. Our discussions with staff on the maternity ward informed us that being able to discuss previous birth experiences was always available either through a community midwife or by staff on the ward. This is also a particular role for the Supervisor of Midwives. On our visit to the unit, a mother was attending for just this purpose. The unit recognised this as being useful in allaying fears from previous births, and although this option was always available, it was recognised that careful handling of the issue by a known midwife was imperative in helping this to happen as some women were reluctant to voice their fears and concerns.

Home Birth

We spoke to several of the 39 women who had had home births in 2013. They rated their care highly for both midwives and paramedics. Of those who had a planned home birth, mothers were really pleased with their experience. Even for the two who had unexpectedly given birth at home they too were full of praise for both midwives and paramedics involved. One had complications and despite a review of practice being undertaken they were never told of the outcome.

Pain Relief

Relatively few women mentioned pain relief when sharing their experiences with us. When they did it was specifically with regard to epidurals. One woman who was overweight (by her own admission) reported that the epidural needle was put in in the wrong place, so she experienced a lot of pain, in her opinion an ultra sound should have been used to locate the correct position.

Further NICE Guidance PH27 Weight management before, during and after pregnancy states that 'An obese woman is more likely to have an induced or longer labour, instrumental delivery, caesarean section or post partum haemorrhage (YU et al 2006) Reduced mobility during labour can result in the need for more pain relief which can be difficult to administer in obese women resulting in increased need for general anaesthesia with its associated risks.[11]

Another reported that the needle had fallen out and this was not spotted by midwives.

NICE CG 55 Intrapartum Care advises that if a woman is not pain free 30 minutes after each administration of local anaesthetic/opoid solution, the anaesthetist should be recalled. [12]

On the Island it is estimated that 65% of the Island's adult population are overweight or obese (IW JSNA 2011-2012) [13] undoubtedly this will impact on maternity services generally and the women that give birth.

The State of Maternity Services (Royal College of Midwives) 2013 report finds that incidences of obesity have more than doubled since 1989. The cost of providing care to these women is estimated to be 37% more. [3]

Food and Drink

There were a few comments regarding food and drink from our community engagement work, The survey did not specifically ask for views and none were received on this topic. Only negative comments were received about food and drink. Most of these centred on catering not being suitable for vegetarians without several days notice.

Mothers who were diagnosed as having gestational diabetes also reported difficulties, and that they received inadequate support in managing their diet, and provision of meals whilst in-patient.

Two to five in every 100 women giving birth in England and Wales has diabetes. Most of these women have gestational diabetes.

http://www.nhs.uk/Conditions/gestationaldiabetes/Pages/introduction.aspx [14]

This is also linked to the prevalence of obesity and will become a growing issue should trends continue as they are projected to be.

There were also comments relating to access to water.

> 'water not brought in for 8 hours, would have been dehydrated if had not brought own liquids'

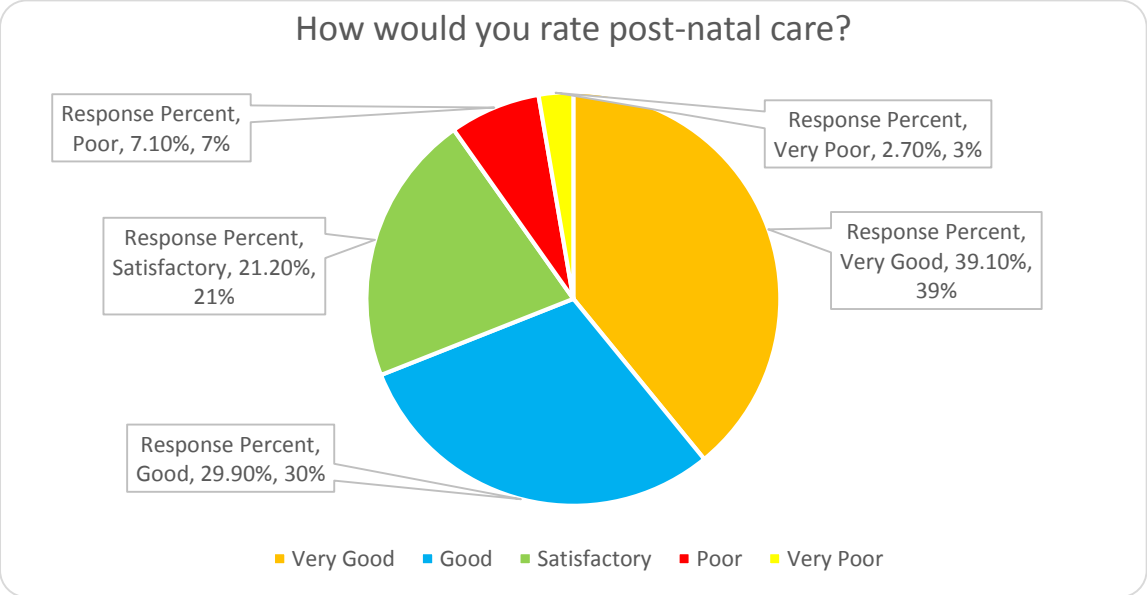
Some mothers were unaware of what the arrangements were for dining and subsequently went hungry.

> 'unsure about food service, was told breakfast was self-service, was unable to leave bed because of cannula and catheter so went hungry.'

7 Post-Natal Care

Figure 4

Responses received through the Healthwatch Isle of Wight Maternity Survey



Following the theme from previous questions post natal care is also rated highly by the survey respondents, but less so than ante-natal and labour/birth care. A higher amount rated their care their care as satisfactory with over 12% rating it as poor or very poor.

Again many women said their care was 'excellent' or fantastic with some women noting that this was despite obvious staff shortages.

Some women felt that they had been discharged too soon, with one or two being readmitted at a later date due to complications arising from the birth which had been missed.

Breastfeeding is mentioned frequently, see chapter 8.

One woman noted that her GP carried out a six week check that she felt duplicated the one carried out by the Health Visitor. Again women noted feeling not informed and confused about why they remained on the ward, and that some staff could be patronising. However, this view should be balanced against the many views expressed by women who had an extremely positive experience.

'I found the staff on the maternity ward to be very pleasant and helpful, but there were rushed off their feet because of the obvious staff shortage'

'I had the help I needed without it being too much...'

Postnatal care for younger mothers was recognised as good by women providing their experiences for this report; they mentioned sensitive care and midwives being very supportive.

Some women thought that they were being discharged too early with advice to call if they had problems; this seemed to be a particular issue for women who had other children and is due to a change in practice at the department. They felt that whilst they were considered as 'experienced' mothers they were not experienced with their new baby. Others described support on the ward as very 'light touch' with second or subsequent babies.

Another commonly held view from community feedback was that the ward was understaffed and that midwives were rushed in their care. There were also several disturbing experiences recounted:

> 'Baby cried constantly for three nights, the mother had no sleep. Only when another mother on the ward offered to take the baby, did staff intervene to give the mother a rest.'

> 'Had CS, couldn't get out of bed to feed the baby, button on call bell didn't work and was sticky, in the end I had to call my husband to come in and help.'

Another parent observed;

> 'A new mother of a jaundiced baby, very anxious, kept ringing for help, midwife removed bell so that calls could not continue.'

Overwhelmingly we were left with the impression that midwives did not have time to provide the care they wanted to due to other constraints and staffing, this was backed up by the view of a midwife working at the unit that we spoke to who stated that this affects morale.

It is always important to balance those who have had negative experiences with those who have provided very positive opinions and we did receive good feedback on post natal ward also, however we did receive less positive feedback on this service within maternity than others.

We understand that the service has now been organised to be more responsive. We have been told that in addition to midwives working on rotation and in the unit. If labour suite is busy, the staff are deployed from the post natal ward to labour suite. Likewise if labour suite is not busy, staff can be deployed to the community to best meet demand. Feedback that we received would indicate that the area not to benefit from this approach is the ward.

> 'My experience of the ward was far from positive, I understand there are staffing issues, but there is no excuse for ignoring a new mum for almost two hours'

Heel prick – Guthrie Test: We had several reports of mothers having to return to hospital for this test when babies were about 3 days old. For mothers without their own transport living in the south of the Island this involved at least two bus journeys and was a major expedition especially if they had older children with them. Another mother reported that she had to attend hospital with her new born for both a Guthrie test and a hearing test, held 3 hours apart, which was very challenging for her.

NICU

For women to give birth then have their babies admitted to NICU is a very distressing experience. Feedback indicates that NICU staff are very caring and helpful and that babies received 'fantastic care'.

There was mixed feedback regarding the enablement of breastfeeding whilst babies were in NICU. Some women reported that they were well supported, one woman noted that NICU went the 'extra mile' in ensuring that she could breastfeed.

Others did not share these experiences. We heard stories of women failing to establish breastfeeding at home after their babies had been bottle fed on NICU. For this group it was frequently stated that the follow up care following discharge was not satisfactory. Another said that she had to be insistent that she breastfed her baby and she worried that other less experienced mothers would be assertive enough to do so. Women were alarmed to learn that their babies had been bottle fed in their absence particularly when they were expressing. We were led to understand that quite often NICU staff formula fed in order to raise a baby's blood sugar, but many women found this very disempowering at a particularly emotional period for them. Clarity about reasons for this policy approach together with consent from parents is required to address this issue. We understand that a breastfeeding peer mentor has been appointed at NICU after parent feedback and applaud this action.

8 Feeding

Figure 5

Responses received through the Healthwatch Isle of Wight Maternity Survey

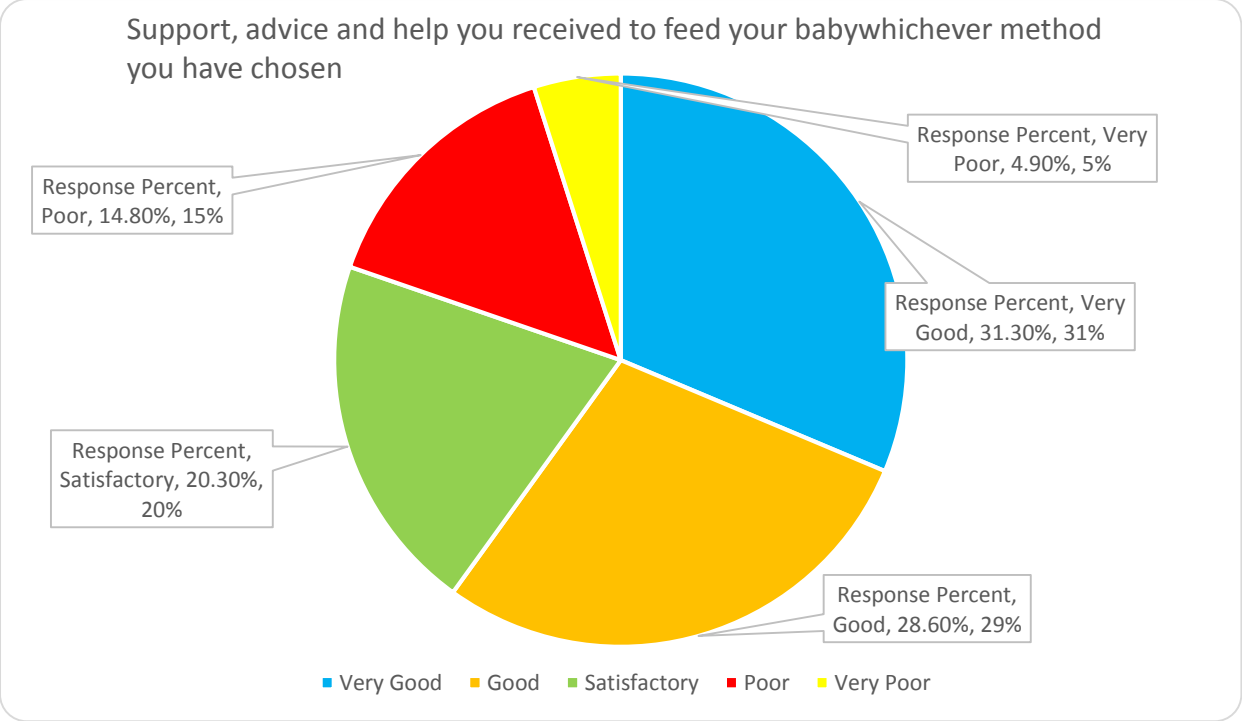
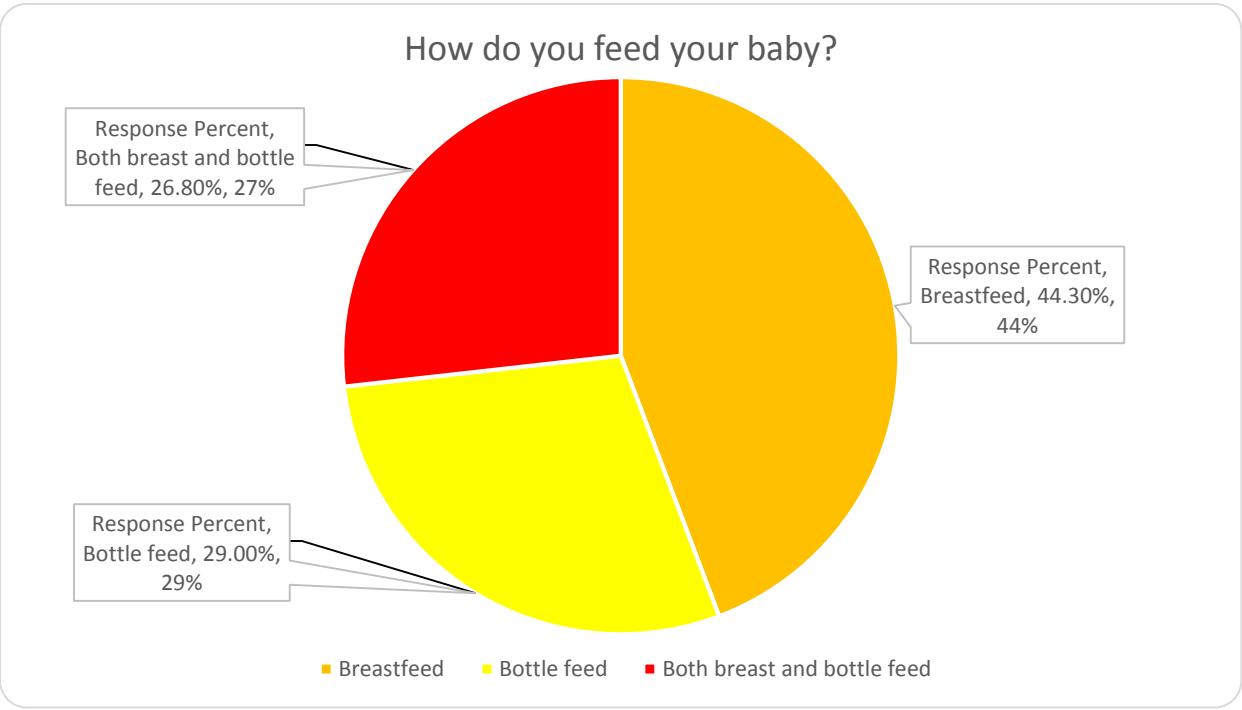
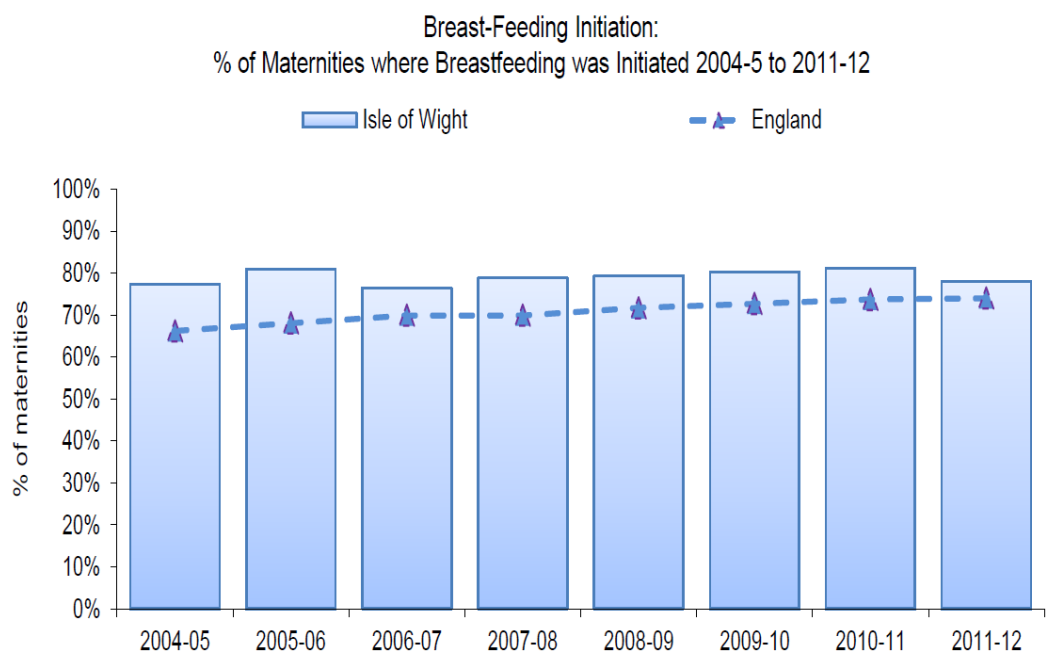


Figure 6

Responses received through the Healthwatch Isle of Wight Maternity Survey



This was a mixed picture and is indicative of the levels of breastfeeding on the Isle of Wight.



Taken from IW JSNA 2013[4]

Most of the comments received in our survey response to this answer were from mothers who had breastfed to start with or who had intended to breastfeed.

Breastfeeding can be very emotional for women and comments were made by mothers during community engagement about being made to feel guilty for bottle feeding or being made to feel guilty because they could not breastfeed for one reason or another. One mother reported having to visit her doctor as she was so distressed by comments made in a Children's Centre relating to the promotion of breastfeeding when she had chosen bottle-feeding.

Differing methods were explained by different sources, creating confusion for those mothers who wanted to breastfeed, with at least one mother being advised by a health professional to 'top-up' with bottle feeding.

The Children's Centres were highlighted by many women as providing excellent breastfeeding support, particularly where these provided a Lactation Consultant they were especially welcomed, with some women noting that where these were not commissioned they had to buy in this consultancy services themselves privately.

The issue of undetected tongue ties, (see chapter 9) was raised with some mothers giving up feeding as they could not get the baby to latch properly, and others seeking the support of an independent Lactation Consultant, often at their own expense.

There was commentary received from parents regarding lack of breastfeeding support and being given conflicting advice. Many parents acknowledged that the reason for this was a lack of staffing on the maternity ward, this was backed up by feedback from a member of staff on the ward. Some parents went further and said that they thought that the maternity department actively discouraged breastfeeding, with one saying;

> 'On admission I was asked 'where is your bottle?'

Good support from some staff on the maternity ward was highlighted, with one account of the maternity ward going out of their way to ensure a mother could continue to express milk whilst undergoing an unrelated procedure in hospital.

> 'Over an hour's individual support with breastfeeding made all the difference.'

Many responses indicated that whilst they breastfed exclusively for the first few weeks, going onwards they mixed fed or used formula milk due to return to work or other pressures. This matches with the statistics mentioned previously.

The Supervisor of Midwives we spoke to, talked about a whole 'toolkit' of methods to successfully breastfeed. It would appear that when this message becomes fragmented that confusion and failure occur. This would appear to be as a result of inconsistent understanding, lack of training, attitudes and time available to support breastfeeding. It is an issue that the department are aware of and are seeking to address through the introduction of the UNICEF Baby Friendly Initiative (BFI).

NICE CG 37 2006 Postnatal care [10]: Routine postnatal care of women and babies recommends that UNICEF baby friendly initiative (BFI) is adopted as a minimum. [15]

The Isle of Wight has a certificate of commitment and is currently working towards BFI status. Healthwatch Isle of Wight has joined the Public Health Department led implementation group for BFI. We spoke to many Children's Centre staff who had undertaken the training through the BFI programme and said it was really valuable.

The NICE guidance 1.3.4 states that Healthcare professionals should have sufficient time as a priority, to give support to a woman and baby during initiation and continuation of breastfeeding, and 1.3.15 'From the first feed, women should be offered skilled breastfeeding support...' [10]

The benefits of breastfeeding to both mothers and children are well documented and need no further explanation in this report. The Healthy Child Programme contains much guidance and information on how best to enable breastfeeding.

NICE Public Health Guidance 11 Maternal and Child Nutrition finds that 'Schemes to promote breastfeeding vary in their effectiveness... However, most established peer and professional educational breastfeeding interventions were estimated to be cost effective...' [16]

Whilst we were informed by staff at the maternity department of Health Care Assistants being deployed in the community to support breastfeeding, none of our feedback reflects this happening.

Parents also appreciated breastfeeding workshops held prior to the birth, support groups such as Baby Café and Breast Friends, together with loans of breast pumps. Views were expressed that learning about breastfeeding should be part of every child's education. Of particular good practice it was noted that teenage parents were encouraged to attend the Breast Friends Group at Ryde Childrens Centre prior to the birth of their child.

The Breastfeeding Group on Facebook started by a parent and is subscribed to by parents across the Island. It was cited by many mothers as providing good peer support and advice.

9 Tongue Ties – Ankyloglossia

An issue that became more evident as the outreach work on maternity progressed was the undiagnosed prevalence of tongue ties.

The NHS Choices website states that tongue ties affect 3-10% of newborn babies and is more common in boys than girls.[17] We remain concerned that tongue ties are not being diagnosed and that sources of help are being sought outside the NHS when they should be dealt with. Appendix 1 outlines the NICE guidance regarding this issue.

The BFI website has the following information for parents to explain more about the effect of tongue ties:

Why divide tongue ties?
Some babies with tongue ties can breastfeed perfectly. Others have difficulty breastfeeding and a few have difficulty bottle-feeding.

For breastfeeding babies, the difficulty is because the tongue tie prevents the baby from attaching efficiently to the breast (failing to latch on). This is due to a combination of the baby not opening its mouth widely, the tethered, short tongue not covering the lower gum, and the disordered movements of the tethered tongue when sucking. The inefficient attachment to the nipple (poor latch) doesn't remove milk from the breast properly and isn't easy to maintain. So, the baby slips off the breast, chomps on the nipple with both gums and then slips off completely. As a result, the baby isn't breastfeeding, but nipple feeding, which is inefficient and can be excruciatingly painful for the mother.

It is very frustrating for both mother and baby, who may 'head-bang' like a rock star, ‘or desperately wave its arms: like they are trying to climb Everest’. Some babies feed inefficiently for a short period of time, get fed up, fall off, fall asleep, and then wake an hour later as they are still hungry, so that they are feeding almost continuously.

Some mothers will their babies to stay asleep as they know that the next feed will be agony, but then feel guilty afterwards. With bottle-feeding babies, the difficulty is that they can't make a good seal around the teat. The suck is inefficient, and the feed takes two to three times as long as for an efficient baby. As the seal is leaky, babies dribble milk in varying amounts, and may need a bib or muslin during the feed or a change of clothes afterwards. [15]

The NCT website states that;

The impact of tongue-tie was overlooked for much of the latter part of the 20th century and some healthcare professionals may not be confident in what they’re looking for.[18]

As recently as February 14 the NCT had written to the Department of Health about this issue, which is clearly a national one. Feedback from mothers on the Isle of Wight indicates this.

‘ Baby was diagnosed with a dairy intolerance when he actually had a tongue tie’

As previously noted, breastfeeding and the aftermath of giving birth for any woman is an emotional and tiring time. We heard from many women struggling to breastfeed for weeks on end and then either through their Children’s Centre or their own efforts and expense resolving the issue through an Independent Lactation Consultant. We also heard from women who had given up trying to breastfeed because of this issue. Women we spoke to raised concerns about speech and language development where tongue ties had not been diagnosed or treated.

‘GP examined me, but not the baby..’

There were too many women mentioning this issue for them to be isolated cases. At the end of the outreach work women continued to contact Heathwatch to tell what had happened to them, where they have wanted to take out complaints we have referred them appropriately. The end result for one parent who made a complaint with the support of local advocates was that at a Local Resolution meeting she was advised that in future tongue ties would be checked routinely for all babies.

We have also recently referred the mother of a young baby to advocates due to what she believes is an undiagnosed lip tie. We understand that that tongue and lip ties are not screened for routinely. Our discussions with staff at maternity informed us that screening is only carried out where there are difficulties with breastfeeding, and that the ENT department were commissioned to deliver the service. Very few of the mothers we spoke to had used the service and there was little awareness that the procedure could be carried out on the Island by the NHS.

10 Children's Centres and Other Service Providers

Nearly 70% of mothers taking part in the survey indicated that they had engaged with a Children's Centre or other similar service.

The IW JSNA 2011-12 states:

'Approximately 80% of parents with children aged 0 to 5 are in contact with or have attended their local Children's centre – this is almost double the national average and is a very useful asset in engaging with parents from a wide range of backgrounds.' [13]

Healthwatch IW did not ask why mothers would choose not to engage with these services, so can provide no views on this point. Most respondents indicated that it was a Children's Centre they attended. There was high praise for the Breast Friends group at Ryde, together with baby massage sessions. All the Children's Centres on the Island were mentioned during our research.

Parents liked being able to see Health Visitors within these settings and as part of other activities at the Centres. One woman stated;

> 'The information is varied and comprehensive. Staff readily give advice or give details of where to get advice from. The content of the groups (e.g. Stay and Play, Drop ins with Health Visitor and breastfeeding group) and social aspect of meeting other mums and their children has been excellent for us'.

Several comments were received regarding concerns in the reduction of services/days open at Children's Centres.

11 Conclusion

Taking account of possible duplicate experiences expressed by women taking part in the outreach programme and the survey, the results reflected are still statistically significant based on the number of babies born in 2013 on the Isle of Wight.

St Mary's maternity department and associated community services, including Children's Centres should be applauded and recognised for the good or very good care that it provides to the majority of mothers throughout pregnancy and maternity. But it should be noted that when things go wrong, they seem to go badly wrong especially in the eyes of the mother, who can find this very traumatic at a time when they feel most vulnerable.

Themes identified around post-natal care, breastfeeding and tongue ties were common in both the survey and the outreach work.

These themes have been discussed with the commissioners and managers of the maternity service and in most instances have already been identified as areas for improvement within the service. The IW NHS Trust has recently reorganised the way in which midwives are deployed, with them now working in the community and in the hospital on a rotational basis, with the aim of keeping all midwives skilled in all aspects of midwifery and based on findings from parental feedback carried out by the department. It is acknowledged that this new system is still being established and that it will be evaluated in the long term. With the ageing workforce amongst midwives there is also a marked staff turnover which has impacted on the service.

The introduction of the Baby Friendly Initiative (BFI) standards and its implementation is welcomed and should do much to resolve the issues that have been raised. Healthwatch Isle of Wight has become a member of the BFI group which is leading the implementation. We will continue to provide a voice for breastfeeding mothers in this group as well as being a critical friend. Implementation of BFI standards is associated with significant improvements in infant feeding practices within relevant health care environments (Broadfoot et al, 2005; Caldeira & Goncalves,2007; Catteneo & Buzzetti, 2001; Figueredo et al, 2012; Kramer et al, 2001).[19]

Since the BFI was introduced, UK breastfeeding initiation rates have risen from 62 per cent to 81 per cent (McAndrew et al, 2012). [19]Government policy (DH, 2010) [20], underpinned by NICE guidance (NICE 2006, 2011 & 2013) [21], promotes the adoption and implementation of Baby Friendly Initiative standards as the best evidence-based vehicle to raise levels of breastfeeding prevalence. Evidence suggests that mothers delivering in Baby Friendly accredited hospitals are more likely to initiate breastfeeding (Del Bono & Rabe, 2012) [19] .The newly revised BFI standards have been developed from the evidence base to inform best practice for infant feeding in the UK and to support women and families to form strong relationships with their babies. [19]

Communication always arises as a key theme in any Healthwatch report. Both communication between professionals and communicating clearly and comprehensively to patients is a decisive way to ensure that they are fully involved and informed in their care. This issue cannot be over-stated.

The prevalence of undiagnosed Tongue Ties is linked to breastfeeding support. Maternity services have not been routinely checking for this condition and it is only considered where breastfeeding is difficult to initiate. Many parents reported that it has caused them a large amount of emotional and physical expense, as well as having a detrimental impact on their ability to breastfeed their babies.

Healthwatch Isle of Wight looks forward to continuing its work in this area, scrutinising and monitoring the largely positive work which is changing the way families experience childbirth.

12 Recommendations

1. More ante-natal work should be done with those who have had previous babies to ensure they feel confident about becoming parents again, specifically:
    - Updates on current practices and options available during pregnancy and labour.
    - Pro-active support around breastfeeding and the networks available.
    - Consistent midwifery support throughout pregnancy.

2. A clear pathway should be developed to ensure Tongue Ties are better understood and able to be diagnosed. This should include the incorporation of a routine check for tongue tie and communication to parents about why each stage of the pathway exists.

3. Specialised breastfeeding support around positioning and attachment is needed for those who have had a tongue tied baby.

4. The BFI work should be fully supported by all agencies with a clearly monitored action plan. This includes ensuring that all relevant clinical staff and children's centre staff should have been released to take part in the 2 day training by the end of March 2015.

5. St Marys Hospital should implement a policy immediately which requires the express consent of mothers on NICU for their babies to be fed using a bottle.

Responses to all recommendations should be received within 20 working days by commissioners and providers of services in line with Healthwatch regulations.

13 Review

A follow up on all recommendations and actions will be carried out by Healthwatch Isle of Wight in February 2015.

14 Appendix 1 -Ankyglossia

Tongue ties – Ankyloglossia

NICE defines ankyloglossia and its treatment ,' is a congenital anomaly characterised by an abnormally short lingual frenulum; the tip of the tongue cannot be protruded beyond the lower incisor teeth. It varies in degree, from a mild form in which the tongue is bound only by a thin mucous membrane to a severe form in which the tongue is completely fused to the floor of the mouth. Breastfeeding difficulties may arise as a result of the inability to suck effectively, causing sore nipples and poor infant weight gain.

Many tongue-ties are asymptomatic and do not require treatment; some may resolve spontaneously over time. If the condition is causing problems with feeding, conservative treatment includes breastfeeding advice and counselling, massaging the frenulum, and exercising the tongue. Some practitioners, however, believe that if a baby with tongue-tie has difficulty breastfeeding, surgical division of the lingual frenulum should be carried out as early as possible. This may enable the mother to continue breastfeeding rather than having to switch to artificial feeding.

If division of the tongue-tie is performed in early infancy, it is usually performed without anaesthesia, although local anaesthetic is sometimes used. In an older infant or child, however, general anaesthesia is usually required. The baby is swaddled and supported at the shoulders to stabilise the head and sharp, blunt-ended scissors are used to divide the lingual frenulum. There should be little or no blood loss and feeding may be resumed immediately'. [22]

NICE guidance states that there is limited evidence that the procedure for division of tongue tie is effective and that further controlled trials should be carried out.

15 Appendix 2 - Responses to Survey

HEADLINES

93% of the mothers taking part in the survey gave birth at St Mary's hospital Newport, IW

Antenatal care

75.4% say the care is good or very good

15% say the care is satisfactory

9.6% say the care is poor or very poor

Care in labour and giving birth

82.1% say the care is good or very good

10.3% say the care is satisfactory

7.6% say the care is poor or very poor

Post natal care

69% say the care is good or very good

21.2% say the care is satisfactory

9.8% say the care is poor or very poor

How babies are fed

44.3% are breastfeeding

29% are bottle feeding

26.8% are combined feeding

This means that 71.1% of babies are receiving some breastfeeding

Feeding Support

59.9% say support is good or very good

20.3% say support is satisfactory

19.7% say the support is poor or very poor

72% access services from a Childrens Centre or similar service.

Age Range of Respondents

Figure 8

This question was asked in the survey in order to give some idea of the age range of respondents taking part.

Answer Options	Response Count	Response Percent
18 to 24	34	19.40%
25 to 34	99	56.60%
35 to 44	39	22.30%
45 to 54	1	0.60%
55 to 64	1	0.60%
65 to 74	0	0.00%
75 or older	1	0.60%

Caring Responsibilities

Figure 9

This question was asked in the survey in order to.....

Answer Options	Response Count	Response Percent
Yes	9	5.10%
No	167	94.90%

Ethnic Origin of respondents

Of the 137 responses to this question all except four, White EU (2) , White American and prefer not to say identified themselves as White, British, English, Scottish or Caucasian.

At the 2001 Census the Island was considerably less ethnically diverse compared with England, with 3.2% of the Island population from minority ethnic groups, including other white groups (13% in England).

2009 estimates suggest that the Island's minority ethnic population has increased to 8.3% of the total, with the greatest increases in the 'white other' and 'Asian/Asian British' groups.

Sexual Orientation of Respondents

All respondents indicated that they were heterosexual.

Conditions Affecting Daily Living of Respondents

A total of 9 respondents identified conditions. Most of these related to anxiety, depression and other mental health issues; others related to physical long term conditions, one respondent raised the issue of cramped housing.

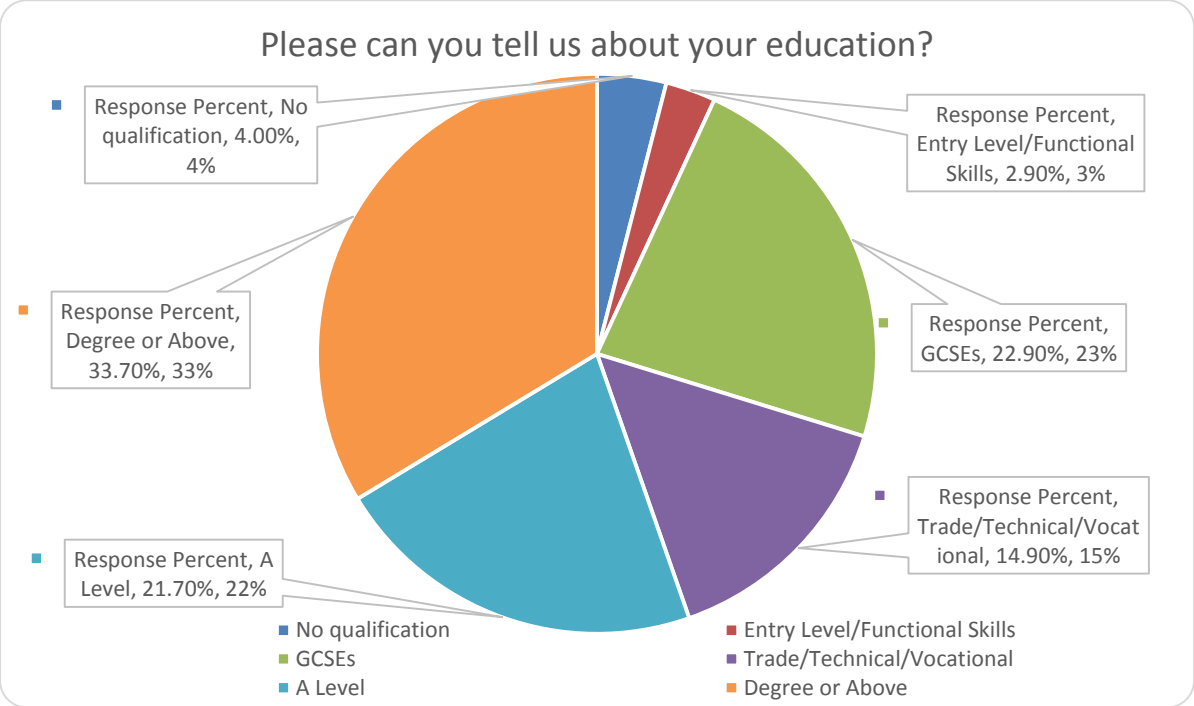
Information about the prevalence of LTCs comes both from self-reporting and from health service information systems. In terms of self-reporting, at the 2001 Census, 20.8% of all Islanders reported that they had a limiting long-term illness, rising to 47.4% in the 65+ age group.

However the Department of Health cites research that 40% of English adults report having a long-term health condition, which, if applied to the Island population, would equate to over 45,000 Island adults.

Educational Background of Respondents

Figure 7

This question was asked in the survey in order to give some idea of the social class of respondents taking part.



Healthwatch Isle of Wight acknowledges that the responses received to this survey are not representative across the Island population with nearly 30% achieving degree level or above. The Island's workforce is less skilled compared with the national and regional averages. A lower proportion has a qualification equivalent to NVQ4 or above (equivalent to a first degree); however a higher proportion has no qualifications at all.

In 2010 24.9% of the Island's working age population had a qualification equivalent to NVQ4 or above (equivalent to a first degree). This compared with 31.3% nationally and 33.9% in the south east region.

At the opposite end of the spectrum, 12% of the Island's working age population had no qualifications. This represented a deterioration compared with the 2009 figure (10.7%), and was also worse than the national average (11.3%) and considerably worse compared with the south east region (8.5%) 20. [13]

Anything else to add..?

The survey asked for any final comments from those responding, of the 181 replies, 62 took the opportunity to make final points.

A good third of these responses were in praise of the maternity department and the care and support received with several staff being named. Likewise Health Visitor and Childrens Centre support was highly rate overall.

Breastfeeding support in the form of the independent Lactation Consultant was mentioned several times, with women calling for this support to be made available universally and on the maternity ward.

Respondents noted that staff were 'rushed off' their feet on the ward and this resulted in inadequate care in some cases, but others noted that despite time pressures staff provided an outstanding service.

> ' ...she was rushing from patient to patient filling out forms and doing paperwork. She had no times to interact with me or my baby. She was obviously unhappy about this but had no choice'

There were a few comments received about inappropriate and patronising comments amongst staff, both midwives and consultants.

Other points raised were cleanliness of the ward;

> '...especially the bathrooms, I was worried I would pick up an infection'

Also issues around communication between professionals and their patients which left parents feeling confused and alienated from the services. The issue of not being able to form relationships with Health Visitors and midwives was raised again, women clearly value continuity of care and not having to keep 'telling their story'

Where care fell short for a minority of mothers this has left them so anxious and fearful that they do not wish to return to St Marys for any further births.

> 'Overall, I was satisfied with my experience; the pleasure of the birth outweighs any memory of the poor hours after. But I know many others aren't so lucky, with breastfeeding support being a particularly poor area. I would welcome (and be happy to participate) in any kind of volunteer peer support scheme to help mothers get a fighting chance of giving their baby the best start in life'.

16 References

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15 UNICEF baby friendly initiative (BFI) - http://www.unicef.org.uk/babyfriendly/

16 Maternal and Child Nutrition: NICE Public Health Guidance 11 - *2008*

17 NHS Choices website - http://www.nhs.uk/conditions/tongue-tie/pages/introduction.aspx

18 The National Childbirth Trust website – http://www.nct.org.uk/parenting/tongue-tie

19 The evidence and rationale for the UNICEF UK Baby Friendly Initiative

standards: (Broadfoot et al, 2005; Caldeira & Goncalves,2007; Catteneo & Buzzetti, 2001, Figueredo et al, 2012; Kramer et al, 2001, Del Bono & Rabe, 2012) - http://www.unicef.org.uk/documents/baby_friendly/research/baby_friendly_evidence_rationale.pdf - ***2013***

20 Government policy: DH - ***2010***

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22 Division of ankyloglossia (tongue-tie) for breastfeeding: NICE PG149 - ***2005***