

Report of Survey Findings:

***Celebrating the Best of the Maternity
Experience of Care with a focus on parents
with learning disabilities***

Supported by



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August 2015

Patient Experience Network
Re:thinking the experience



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Introduction

This is a summary report of a survey that was undertaken by PEN in partnership with NHS England and CHANGE.

The survey was prepared to support a report commissioned specifically to explore the maternity experience of care for parents with a learning disability. We therefore updated a survey PEN ran in 2014 to include additional questions focussing on provisions for parents with a learning disability. This report therefore compares the results with the survey from 2014 where relevant and explores specific provisions for parents with a learning disability.

The survey was open for responses from 24th February 2015 until 15th April 2015, and was an on-line survey. Ruth Evans of PEN, Catherine Carter of CHANGE and Kath Evans of NHS England extended invitations to their respective networks to take part. Upon closing we had 107 participants. We would like to thank everyone who contributed.

When reading this report it may be useful to refer to the other reports focusing in the maternity experience. These are:

- The full report exploring the maternity experience for parents with a learning disability. This report is called “Hidden Voices of Maternity – *Parents with Learning Disabilities speak Out*” published in August 2015
- The original survey results report called “Report of Survey Findings: Celebrating the Best of the Maternity Experience of Care May 2014”
- The report on the Maternity Experience of Care called “*Improving Service User Experience in Maternity Services*” published in May 2014

These can all be found on www.patientexperiencenetwork.org/resources or by contacting PEN. Our full details are at the back of this report.

Executive Summary

- In total 107 participants from 80 different organisations took part in the survey in 2015 (February – April). This is a small increase from 94 in the previous year.
- As always with surveys of this kind the results may be skewed by the very nature of the survey itself, the audience who have been approached and indeed have then decided to take part. That said, what is clear from this survey is that many organisations are working hard to improve the experience for parents including those with learning disabilities and other vulnerable groups.
- Participants represent a wide range of interested parties including NHS England, commissioners, providers, and other organisations. Nearly three quarters of the respondents (71%) were from Trusts (Acute and Foundation), 8% from Commissioners and central bodies with 7% from GP practices. [See Appendix 1](#) for more information.
- Over half of the respondents were midwives – across various levels and specialties, 10% were consultants and 7% from GP practices. Directors, managers and social workers were also amongst the participants. This audience is more homogenous than in the previous survey. [See Appendix 2](#) for more information.
- We asked participants how many births were delivered in 2014. For the GP practices that responded this ranged from 27 to 110 with an average of 50 per practice. For the maternity units this varied from 703 to 16000 giving us quite a range in size of unit. [See Appendix 3](#) for more information.
- In terms of the respondents view of their organisation's focus on maternity experience, we saw an increase in the focus by almost half a point from 7.87 to 8.33, indicating a positive shift in focus for the participating organisations. There was a general shift to higher scores, although the proportion of people giving their organisation a score of 1 remained the same, possibly indicating a minority of organisations that are not yet focussing on experience.
- Interestingly, as before, a third of respondents gave their organisation the maximum score with comments indicating that they already *"focus all of our care on the patients' experience"*. On the one hand this is reassuring; on the other does this confidence mean there is limited ambition and drive to improve. [See Appendix 4](#) for more information.
- There has been a significant shift in the number of organisations reporting that they have a strategy in place specifically for the maternity experience with 79% saying they have one versus 57% in 2014. [See Appendix 5](#) for more information. Of those who said they did not have a strategy several observed that there were plans in place - *"it is included within the business units strategy but we are about to develop a separate strategy"*. The comments demonstrate a more upbeat response than in the previous year with all organisations understanding the importance of the strategy and in many cases it is being driven by the head midwife.
- It is perhaps unsurprising, considering the backdrop to this survey, that there are many priorities listed by the survey participants. The top priority for respondents is staffing moving from 5th place in 2014, with improving service user involvement remaining the second priority.

Executive Summary *(continued)*

- Patient experience of care, top in 2014, comes in different guises with Postnatal care and experience in third place and 1-2-1 care in 5th with continuity of care in 4th (up from 8th in 2014). ([see Appendix 6 for the full list](#)).
- Important areas mentioned in 2014 but not raised in this survey include a focus on fathers, families and partners, bereavement and breastfeeding. It is evident in some of the commentary that some work is in progress certainly for bereavement and support for fathers, but it is still surprising that these important areas were not listed as key priorities in the 2015 survey.
- Survey respondents were invited to share how they collect feedback today and what plans they have to improve this plus how they have used the feedback in their organisation. ([See Appendix 7 for ways of collecting feedback](#)). As may be expected FFT is the top vehicle mentioned by the majority of respondents. Ranked second with surveys, Facebook is a key vehicle. Both Facebook and Twitter are mentioned more frequently than face to face. Complaints or concerns are also seen as important mechanisms for feedback. Targeted events were not mentioned in 2014, and are now a key mechanism for feedback and particularly when reaching vulnerable groups and people who may not respond to more conventional mechanisms.
- About a quarter of respondents indicated they have no plan to change the way they collect feedback. The others expect to increase the use of social media, the use of apps/ ipads/ electronic media to collect feedback and find ways to encourage participation from the “harder to reach” groups. One of the interesting ideas was the use of stories for a video library.
- As may be anticipated feedback is actively used in the participating organisations to “To improve services and highlight good practice”, “To celebrate good care and identify where we can improve/ debrief where specific issues raised/ to focus and identify areas of improvement” and “to motivate staff”. “You said - we did” is frequently mentioned as an important part of the process both for staff and service users, and feedback Friday is one idea put forward by one participant.
- There are many great examples of action being taken as a result of feedback, many of these relate to bereavement services, and support for fathers, two areas highlighted as priorities in the 2014 survey. ([See Appendix 8 for the full details](#)).
- We asked a series of questions specifically about the maternity experience for parents with a learning disability. This is summarised on the following page.
- In 2014 in summarising we commented that overall there is much good work and solid activity being undertaken focussed on improving the experience, however, in many cases this is more around building robust foundations rather than innovative or stretching ambitions when comparing to other areas of care. And in 2015 this remains true. Many of the activities listed in the survey would be considered the norm in other areas. This is not to understate their importance as these are critical foundations, but what it does indicate is that this area of care may be slightly behind the patient experience curve in terms of personal ambition, vision and practical activities. One respondent’s simple comment “[we provide an excellent service](#)” perhaps captures the nub of the issue – this may be the case but how do you create a constructive discontent around the organisation to strive to be even better?

Parents with a Learning Disability

- Participants in the 2015 survey were asked what proportion of their births were to parents with a learning disability. Estimates ranged from less than 0.5% to 5% but the majority estimated 1 or 2% which is in line with national estimates.
- We invited participants to share what resources they have to support these parents. These are listed in Appendix 9. The most frequently mentioned resource was easy read leaflets. This was mentioned by only a fifth of the participants and yet these are already available.
- There is limited training in place focussed specifically on maternity and learning disabilities and this is a key area put forward by participants to address moving forward.

Areas to improve

- Areas put forward to improve the experience for parents with a learning disability included in addition to training:
 - Awareness of the various learning disabilities and how this may affect behaviour
 - Better means to identify parents
 - More literature in an appropriate format
 - Additional capacity to offer one to one care
 - Named contact and continuity of care
 - Better communication with key workers and multi agency meetings
 - Facilities for the carer to stay

Support required

- To help them achieve this they suggested the following support:
 - Commission specialist midwife roles
 - Development of easy to read leaflets
 - Specially trained staff
 - Designated worker allocated to each client
 - Allow additional time for continuity of care
 - Evaluation with an award that is nationally recognised as being sensitive to the needs of these parents
 - Guidance to help identify the parents
 - Training of staff



We already provide extra provision for clients with a Learning Disability and have an 'Easy Read' version of pregnancy notes, and allow for a double length appointment for all clients who have an identified Learning Disability, and have a Policy for care of clients with LD. However, in the longer term we need to make additional provision to 1. increase awareness further around LD especially for clerical staff who are non clinical 2. Consider the appropriateness of signage within Trust and ensure this meets LD needs. 3. Consider having LD Champions and an LD Steering Group.

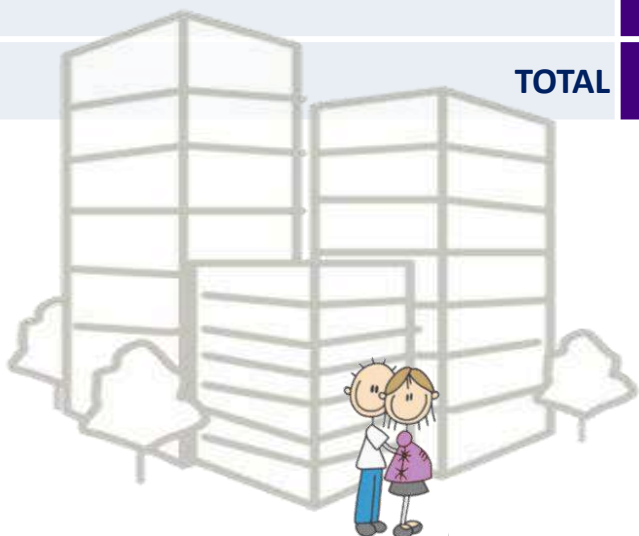


Appendices



Type of Organisation

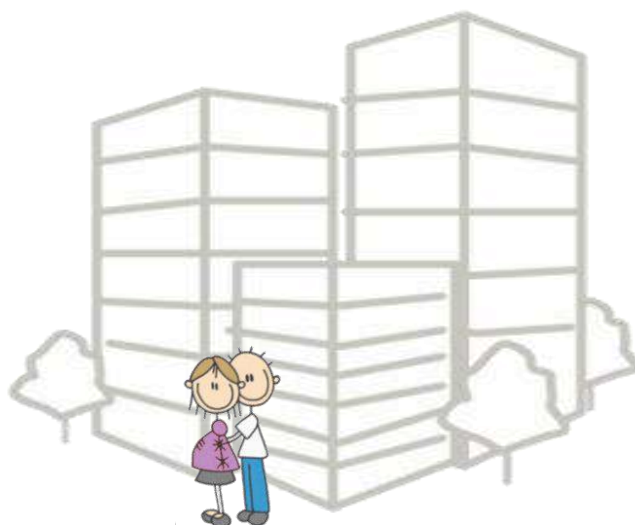
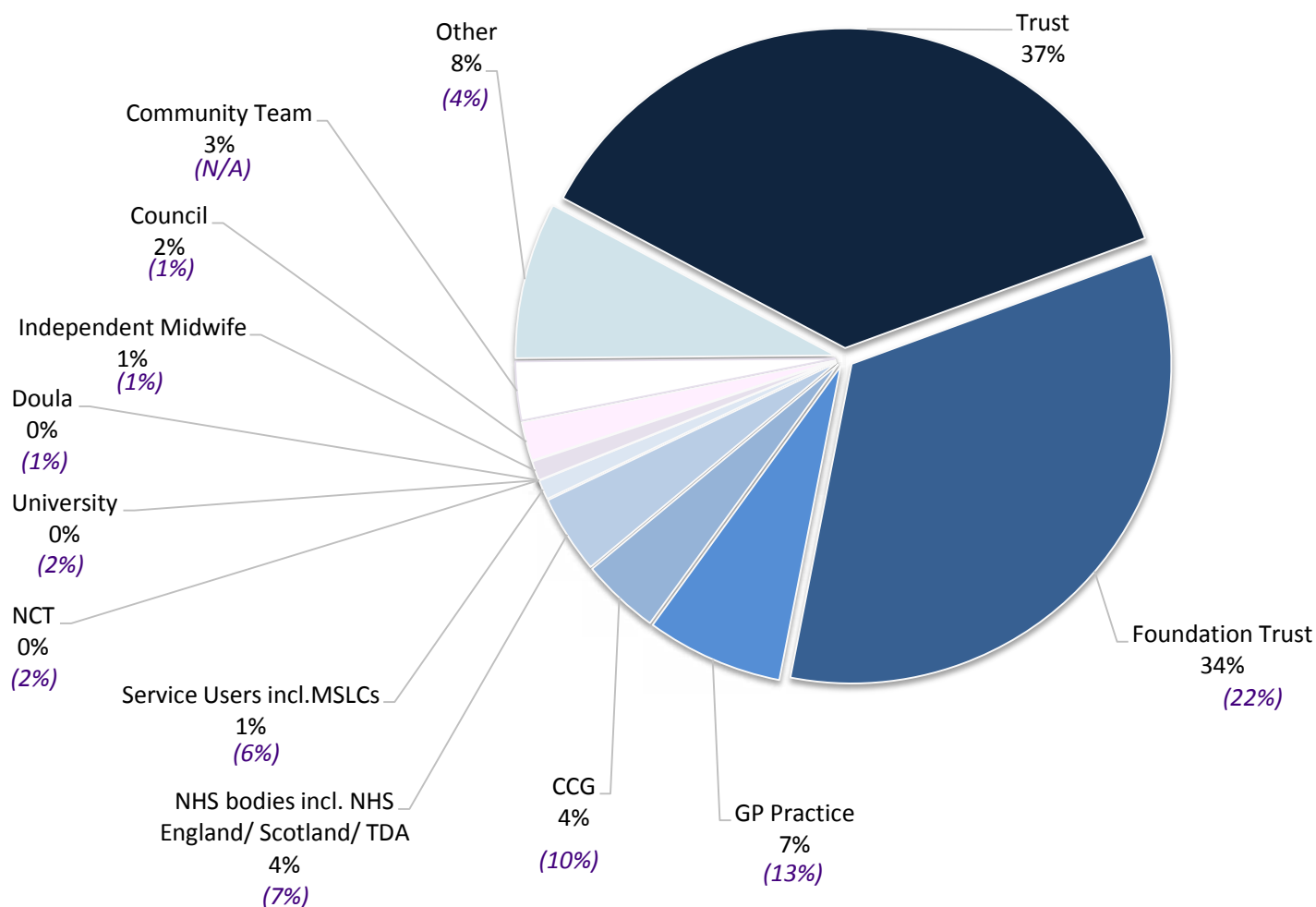
Organisation Type	2015 TOTAL	%	2014 TOTAL	%
• Trust	42	37	28	30
• Foundation Trust	38	34	21	22
• GP Practice	8	7	12	13
• CCG	5	4	9	10
• NHS bodies incl. NHS England/ Scotland/ TDA	4	4	7	7
• Service Users incl. MSLCs	1	1	6	6
• NCT	-	-	2	2
• University	-	-	2	2
• Doula	-	-	1	1
• Independent Midwife	1	1	1	1
• Council	2	2	1	1
• Community team	3	3		
• Other	9	8	4	4
TOTAL	107	100	94	100



Type of Organisation

Total number of organisations = 107 (94)

Key
(2014 Comparison)

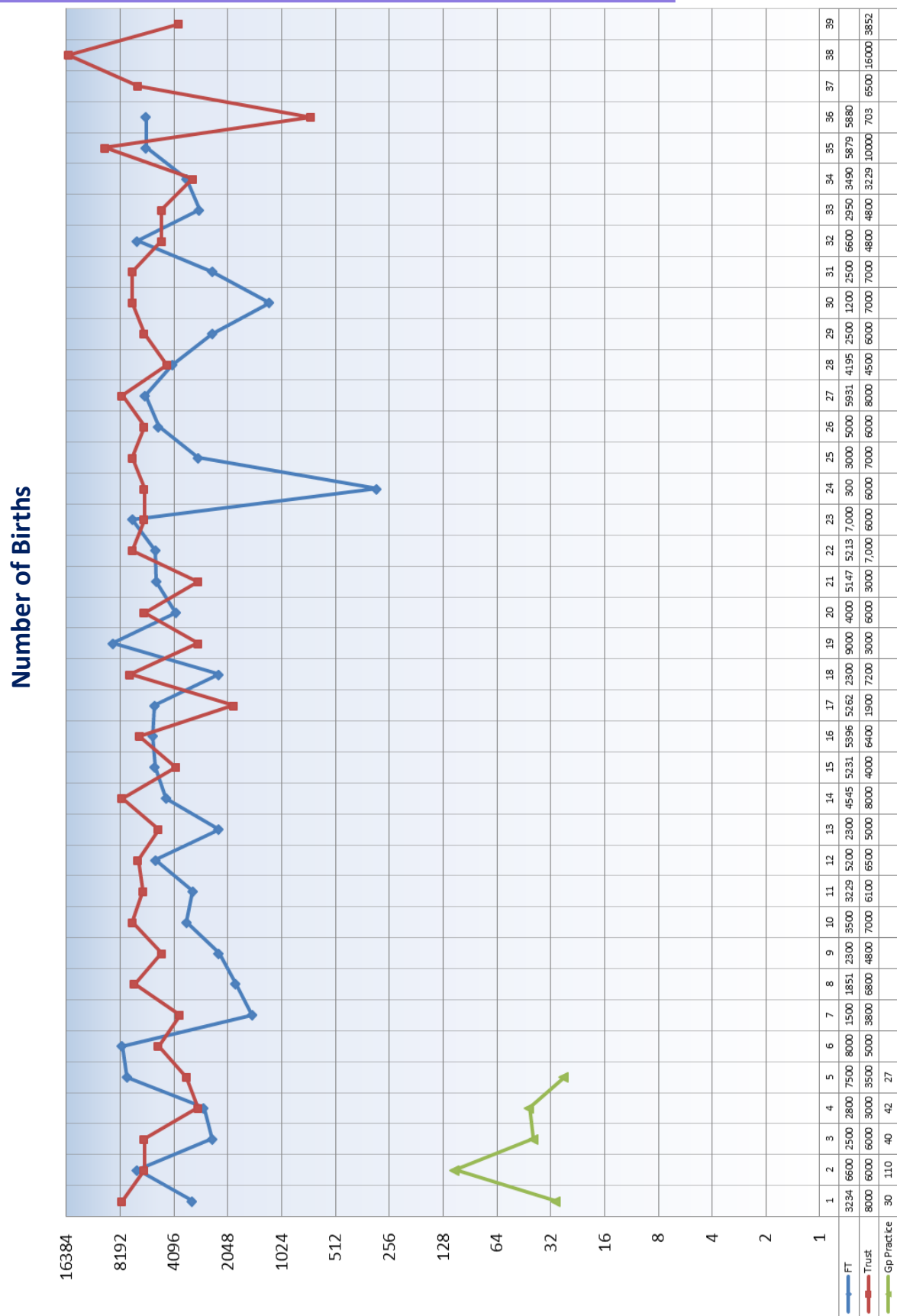


Role of Participant

Respondent Role	Number	%
Midwife incl community/ specialist	27	25
Lead midwife/ matron	10	9
Head of midwifery/ consultant midwife	23	21
Consultant Obs/ Gynae/ Paed	11	10
Practice Manager/ GP	8	7
Director	5	5
Commissioning Manager	3	3
Manager – service/ project/ experience	9	8
Social Worker	3	3
Other	8	7
TOTAL	107	100



Number of Births Delivered in 2014

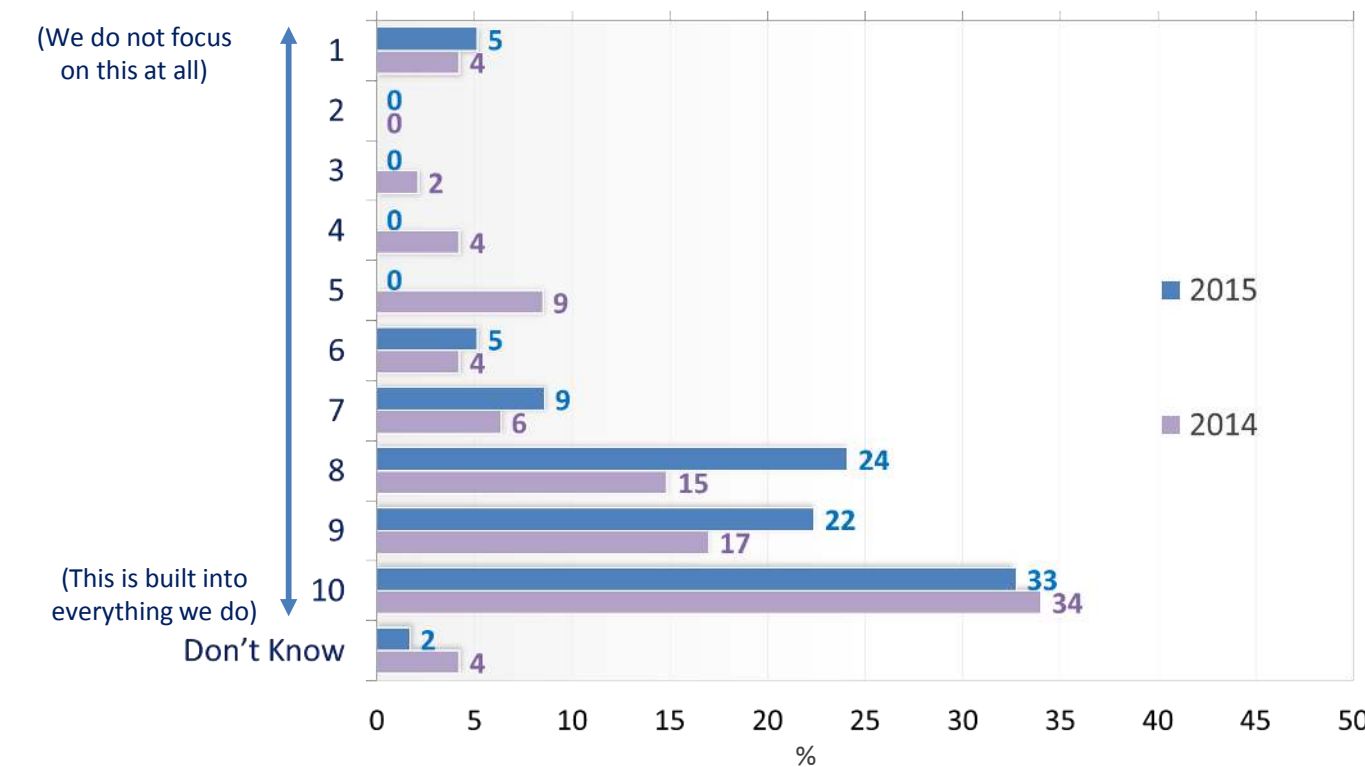


Overall View of Organisational Focus

Thinking about your own organisation, how would you rate your focus on the experience for maternity? Please rate your organisation on a scale of 1 to 10 where 1 represents 'We do not focus on this at all' to 10 'This is built into everything we do'

Answer Options	No. of Respondents 2015	No. of Respondents 2014
1 (We do not focus on this at all)	3	2
2	0	0
3	0	1
4	0	2
5	0	4
6	3	2
7	5	3
8	14	7
9	13	8
10 (This is built into everything we do)	19	16
Don't Know	1	2
Response Count	58	47
Rating Average	8.33	7.87

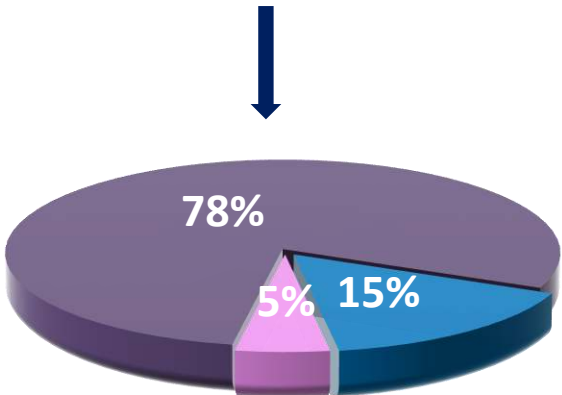
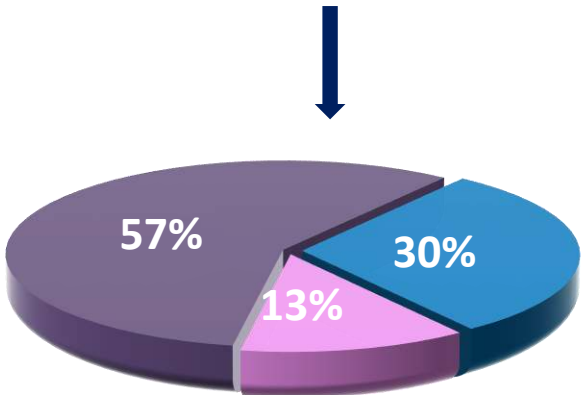
‘Focus on the experience’ - Comparison between *Maternity 2014 & 2015*



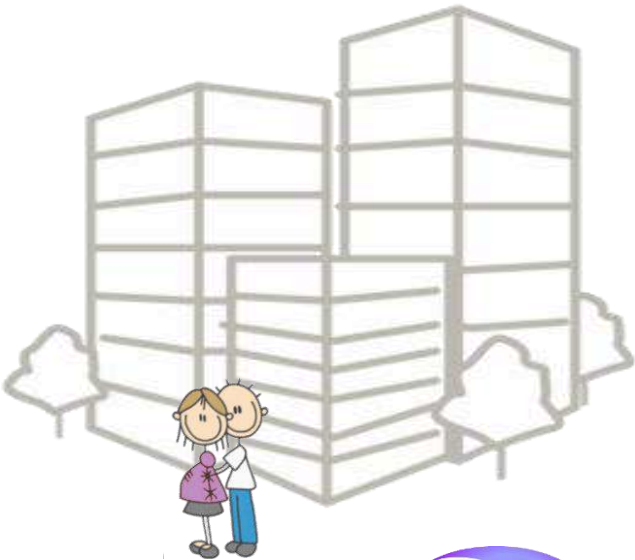
Strategy for Maternity

Still thinking about your organisation, do you have a strategy focussed specifically for the maternity experience?

	2014 Count	2015 Count
Yes	27	45
No	14	9
Not sure	6	3
Response count	47	57



■ Yes ■ No ■ Not Sure



Priorities for Maternity

Rank 2015 *	Rank 2014	Issue	Mentions
1	5	Staffing	10
2	2	Listen and act on service user feedback	6
3		Postnatal care and experience	6
4	8	Continuity of care	6
5		121 care	5
6	7	Facilities/ environment	5
7		Communication	4
8		Improving women and partners experience during labour	4
9		Involve users in shaping services	4
10	6	Midwifery Led Unit	4
11	14	Access	4
12		Promoting and facilitating natural birth	3
13		Supporting providers to promote choice	3
14	3	Improve communication networks within and outside Trusts	3

**Ranking defined by 1st, 2nd, 3rd choice of priority mentioned*

Ways of Collecting Feedback

Rank 2015*	Rank 2014	Mechanism	Mentions
1	1	FFT – score and comments	50
2	4	Facebook	21
	6	Surveys	21
3	5	Twitter	18
4	2	MSLC/ Support group	15
	10	Complaints/ concerns	15
5	9	National Patient Surveys (Picker/ CQC)	13
6	3	Face to face/ direct at bedside	12
		Targeted events e.g. for vulnerable groups	12
7	19	Audits	11
8	7	Compliments	9
9	11	PALs	7
		email	7
10	18	NHS Choices	6
	8	Website	6
11		Cards	5
	26	Peer reviews/ staff feedback	5
12		Birth After Thoughts service	4

Rank 2015	Rank 2014	Mechanism	Mentions
13		Collaborative working	3
		Letters	3
		Debriefs	3
	26	Bedside TV	3
		Inspections/ walkarounds	3
14	26	Care rounds	2
	22	Your opinion counts	2
	26	Mumsnet	2
	24	Birth Stories	2
15		Patient Choices	1
		Student midwives	1
		SLE/ SUI	1
		Texting	1
		Maternity Safety Thermometer	1
		Suggestion box	1
		Incidents	1
		Datix reporting	1
	26	NCT	1
		Thank yous	1

*Ranking defined by number of mentions

Action on Feedback in Last 3 Months

Respondents were asked to give an example of how feedback has been used effectively in your organisation in the last 3 months.

Actions included:

Birthing partners are offered the opportunity to stay overnight with their partner following the birth of their baby. Based on patient feedback, we have purchased recliner chairs to improve their comfort. -Development of a dedicated bereavement suite to provide patients and their families with a bespoke environment to allow additional privacy and dignity during this difficult experience.

Allowing Fathers to stay within the unit over night

Celebration of care; individual feedback to encourage midwives and the team as a whole; involvement of user representatives in development of meadow birth centre; changes in practice in relation to comments/ complaints

Partners wanted extended visiting and opportunity to stay overnight. that now happens.

Real time patient feedback has been used to identify areas of care which has led to changes in practice being delivered ie patient self administration of medication in maternity services. Also facilitated time out /training opportunities for MDT staff groups in maternity to further develop skills in delivery of compassionate care.

From Baby Friendly Initiative visit; from complaints, to address MAU experience.

Ear buds and eye masks are available for women finding it noisy on postnatal wards Art and play activities are offered for children in busy clinics at half term holidays Volunteers welcome patients and signpost them to car parks, reception desks and reception desks as appropriate.

The use of in paper surveys to inform how effectively women who are discharged early following delivery are supported in the community

Looking at the quality of experience for non contracted service providers.

Feedback from women who have had bereavement support and how we can do things differently.

Following a concern raised around the information given to patients following foetal loss our specialist Bereavement midwife is creating and updating the information leaflets .

Improvement in facilities for bereaved parents following feedback. Changes to visiting times - times extended for partners

Individual who required access to Sign interpreter, all details were available in day light hours but not available out of hours, now made arrangements with local sign group , who will provide out of hours service

It has resulted in simple changes to blinds in an examination room to ensure greater privacy and dignity for the woman to more whole scale change such as the introduction of two new birthing suites, post date holistic clinic, options clinic, VBAC clinic .

Visiting times for partners on the postnatal ward extended due to feedback that the time allowed was too short. Partners being able to stay on the antenatal and postnatal wards if the women want them to - there are now camp beds and chairs available for partners to stay.

About to launch an on-line e-learning learning disability awareness programme

Coffee Machine in Labour waiting area

Help to fund capital programme for improving ward environment visiting times have been changed Investment in Infant Feeding team and targeted support for primips breast feeding developing new information leaflets and the new trust website, implementing a new dedicated triage-line contact in labour system to support women's access in early labour,

Access to service inform commissioners of service developments change of clinics

Now have birthing pool available for women to use on acute labour ward, for some time women had been voicing a request for this facility

Action on Feedback in Last 3 Months (continued)

Respondents were asked to give an example of how feedback has been used effectively in your organisation in the last 3 months.
Actions included:

- A video of a woman’s story recently used at MSW study day feedback was it was very powerful
- Many comments that women would like partners to stay during the induction of labour process and following c section currently in the process of making arrangements for partners to stay in these circumstances
- Improved the environment. Improvements in birth prep provided.
- Due to reconfiguration of the services patient feedback has been a very important element in the evaluation of the maternity services and have involved community health councils feedback gained through public website information
- The introduction of a VBAC in water service for high risk women in labour
- Aspects of staff attitude impacts on the patient experience more than some staff realise
- Bereavement room decor and use has been changed.
- In my new role as Midwife For Long Term Conditions I have recently been involved in the care of a women with a learning disability. I have been able to use this experience to help towards care planning for women in the future. I found the feedback from her family very informative and I have worked with our Learning Disabilities Nurse for the Trust.
- Postnatal ward discharge procedure improved
- Monthly staff bulletins
- Development of perinatal mental health pathway
- complaints about cleanliness has led to review and uplift of the cleaning contract
- Partners staying overnight was a longstanding issue and in recent months positive feedback has been received from women saying how much they appreciate the support of a family member.
- A recent complaint has led to the woman being filmed and telling her experience of using our maternity service and how this impacted on her and her family . This film will be used for staff training to improve communication and care provision. This film will be used throughout the Trust, not just the maternity service
- Disseminated in weekly bulletin
- Core staff implemented to increase continuity
- Further development of a designated debriefing service
- Parents of babies in NICU suggested improvements to facilities for parents. Environment changed. New furniture ordered and drinks machine purchased.
- Positive feedback from users showing that Great Expectations programme is being effective in support change process of staff attitudes and conduct
- Review of patients records.
- Improvement to meal times
- Improvements to car parking
- Creating a bereavement suite

Resources Readily Available for Parents with Learning Disabilities

Resources	Mentions 2015	Mentions 2015 (%)
Easy Read leaflets	19	21
Learning Disability Nurse or team	12	13
Easy read booklets e.g. My pregnancy, my choices	6	7
Pictorial information	6	7
None	5	5
One to one parent education and support	4	4
Aids/ Models/ Dolls	4	4
Family members facilitated to stay through patient journey	4	4
Verbal/ audio interactions	3	3
One to one midwifery care	3	3
Learning Disability passport	3	3
Specialist midwife	3	3
Named community midwife	2	2
Physical and learning disability pathway	2	2
Translators/ interpreters	2	2
Equality and diversity lead to provide guidance if required	1	1
Birth plan	1	1
Support workers to give extra care	1	1
Tailored service	1	1
Early help assessment	1	1
One to one FSW	1	1
Trained in signing	1	1
Don't know	1	1
Toolkit for supporting parents with a learning disability	1	1
Patient advocates	1	1
Extended time	1	1
Established carers	1	1
Encourage advocates to accompany patient	1	1

Examples of Good Practice

Respondents were asked for a brief description of Good Practice activities related to Maternity experience for parents with learning disabilities

Examples included:

We accommodate partners on the ward overnight and are able then to support them as a couple and identify any specific areas of need re. parenting and target these. We develop a bespoke birth plan with communication/ consent prior to the time of birth.

Where parenting support and assessment is required beyond this, we admit our mums and babies to the transitional care unit where the midwife and nursery nurse can work with them to ensure they are appropriately supported, needs identified and addressed and that the baby is safe to go home with the parents with ongoing input from community midwife/ family support workers (community). The community midwife teams all have a designated specialist midwife who either supports the community midwife with her caseload or adds these ladies to her own smaller caseload to ensure they receive enhanced continuity of care. We have had recent experience of caring for a couple who were blind – a pre-birth tour of the unit was facilitated and the room allocated to them for post birth care was rearranged to suite their needs – partner stayed with the mother and both were supported together to care for their baby.

Safeguarding team support midwifery and support staff to put the appropriate package in place for personalised care

-The Hospital has a dedicated Safeguarding Midwifery team

Good use of Multi disciplinary working using BSL Interpreters, Adult SW, Hospital staff to allow extra explanation for a profoundly deaf woman with LD who requires Gynae Surgery. Used Hospital communication book to explain what would happen after surgery.

If any women has a disability she will be offered a home visit to assess and plan for any additional needs she may have with regard to maternity care

We have 2 public health midwives working in Knowsley who provide care to vulnerable women which includes women with learning disabilities and other vulnerable groups. They link in with many services to provide tailored care e.g. obesity pathways and links with slimming world and other groups.

We did work very closely with all agencies involved with a patient recently who had a learning disability and had frequent multiagency meetings throughout her pregnancy and following delivery which enabled us to all support the family more effectively. We aim to make this the norm in all cases in the future. This lady did have a very effective support system already in place.

We have a number of initiatives for vulnerable families including

1. Caseloading of women in prison including safeguarding, pregnancy support and scanning at the prison, mother and baby unit in prison with parenting skills taught. Two safeguarding midwives caseload the prison women and babies.
2. Perinatal Mental Health Midwife with a focus on community based care and liaison with mental health agencies.
3. Birth Reflections Service for women and partners suffering following difficult birth, birth trauma, depression and needing counselling.
4. Bereavement midwifery team – giving support follow stillbirth and pregnancy loss.
5. Enhanced postnatal pathway for women and vulnerable families requiring extra support, help, advice and observation.

1. Traveller families Invited by family to record their experience as users of the service. This was then shared with providers. This reflected the following insight – mainstream services appear to wary of large groups attending the unit in support of their family member and are struggling to provide the reception desired. A work in progress.
2. Young mums and mums to be Invited personally to attend a community event in a local church in the centre of Chester city to be pampered free of charge. Nails, make up etc. A one stop shop was created in this pop up session for one afternoon. The young mums met future staff and signed up to groups such as parenting sessions; one agreed to retry to lactate with her baby following contact with breastfeeding Hv specialist.

Teenagers team Midwife specialists in mental health, substance misuse

Mainly through individual care plans and working with the services already in place for the mother

Mainly the community midwife is aware of a families problems and will endeavour to secure adequate support for them thro the appropriate channels these can sometimes be difficult to access due to communication with the LD team

Examples of Good Practice (continued)

Respondents were asked for a brief description of Good Practice activities related to Maternity experience for parents with learning disabilities
Examples included:

Myself & my colleague run a service of extra advice & support to young people, which includes those with learning difficulties

Both parents would stay in the postnatal ward to ensure parenting skills etc. resulted in the family being equipped to take baby home. We have baby showers for hard to reach parents. Planning grandparent event in hard to reach areas.

We have a dedicated team of 3 specialist midwives who care for the most vulnerable 2% of our local population offering enhanced, individualised care to meet each families needs.

We have a Disability action and awareness group which has service users and staff as members. We have a folder available for each midwifery team with resources available. We employ a Disabled Public Health Midwife

I was a part of the recent care of a woman with a learning disability in my position as Midwife For Long Term Conditions. I made sure I was available to see her when she came into hospital for antenatal appointments, so she always saw a familiar face. I worked with the woman, her partner and mother to produce an individualised plan of care to ensure her experience of our maternity services was a positive one.

Mother with Friederichs Ataxia wheelchair bound care provided by Vulnerable team midwife in her area. Birth planned for another site with antenatal birth plan multi-disciplinary meeting to plan birth and postnatal care in hospital. Breastfeeding support and parenting support planned and implemented after the birth. MDT discharge planning meeting held with hand over of care back to original vulnerable team midwife. Postnatal care at home.

We have a team of midwives providing additional support for women from vulnerable groups, providing continuity throughout the pregnancy episode. This team link closely with safeguarding team and social care services.

Re development of pathway-aids staff in directing to appropriate care & support which improves service user's experience. We have a 'One stop antenatal clinic' for those with substance abuse. We work closely with the following working with vulnerable groups:- NSPCC and alongside their 'Baby steps programme' Integrated Care Pathway (ICP)-a preparation for parenthood programme in the Children Centres. Involved with Family Link workers (FLAN) Work with the Family Nurse Partnership Programme (FNP) Bradford about to start the 'Better Start Programme'. Ties with 'Here we are group', newly started 'Birth Choices group' and work closely with the Bradford & Airedale 'Maternity Partnership' group. 1:1 Parent Education is offered with Specialist Midwife in Parent Education together with HFN/support worker to prepare those with LD or any specific needs for the rest of their pregnancy, forthcoming birth & becoming parents. Visits to Labour Ward, Birth Centre & wards all offered & undertaken to help reduce anxiety of coming into a new/strange place. Consideration given to involving a doula for birth support & possibly post birth.

Community midwives routinely ask about learning difficulties / disabilities for all women and refer to the Specialist Midwives for additional support and planning. Joint pregnancy and birth planning with appropriate agencies as soon as possible to ensure appropriate support provided to women and their families to meet their individual needs. All vulnerable, hard to reach and women with disabilities are referred as above and pregnancy and birth planning undertaken if appropriate for the individual

During time on Community was instrumental in organising & running AN class for vulnerable mothers i.e. No English, disabled, teens, anyone in need. Set up leaflets in other languages in conjunction with council run assoc. Teenage pregnancy Midwife & team. Specialist Midwives in all vulnerable areas.

A Few Words About PEN and CHANGE



CHANGE is a national human rights organisation led by disabled people. CHANGE employs people with learning disabilities to co-lead and work alongside a non-learning disabled colleague for an equal salary. People with learning disabilities at CHANGE use their expertise to educate health and social care professionals to improve their practise. CHANGE supports people with learning disabilities to consult peers and lead projects to tackle discrimination and participation in society fully as equals.



PEN is a not for profit organisation whose ambition is to recognise, celebrate and share what is working well in the experience of care. PEN has written a series of reports to highlight the great work in the maternity experience of care, children’s and young people’s services and the experiences of families with children who are long term ventilated, amongst others.

To find out more please visit our websites:

www.patientexperiencenetwork.org or www.changepeople.org

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Patient Experience Network

Re:thinking the experience

