How service users’ perspectives are shaping the future of maternity care

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In *Better Births*…

Baroness Cumberlege wrote to women:

- “You took the time to share with me your reflections on the care you received – both good and bad. I heard inspiring stories, but also heart-breaking experiences. The insight you have given into what matters to you, what could be better and where things are already great, has been tremendously helpful and at times deeply moving.”

Review team visits

• Over the 9 months of the maternity review, there were 57 visits to maternity services and community-based events.
‘Drop-in’ events
At each event, people could:

- Talk to members of the Review Team
- Contribute to a comment wall
- Cast their vote on local maternity services
- Post ideas to the Better Births post-box
- Engage in discussion with others around the ‘Whose Shoes?’ game

Private rooms were available every time for conversations with people who wanted to share difficult or traumatic experiences.
Online feedback

National Maternity Review
Online Survey Analysis

NECS Consultancy Unit

Q 2.9 Same midwife before, during and after birth (Antenatal care) - Benefits

There were 206 comments relating to benefits, these have been broken down further into five sub groups. 83 (40%) comments were around the ability to build trust. 63 (31%) comments stated it would be helpful in knowing history and identifying problems and 50 (24%) comments said that this would prevent them from needing to repeat themselves.

Build up trust
- “Pregnancy is such a vulnerable time and being able to create a trusted bond with your midwife is essential.”
- “Consistency ensures that the midwives build a relationship with the mother and this then prevents loss of information on both parties”

<table>
<thead>
<tr>
<th>Sub Group</th>
<th>No. of comments</th>
<th>%</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Build up trust</td>
<td>82</td>
<td>40%</td>
<td>You would be able to build up trust more easily</td>
</tr>
<tr>
<td>Quality of care</td>
<td>63</td>
<td>31%</td>
<td>Would improve the standard of the treatment and care provided and prevent problems with inaccurate medical notes</td>
</tr>
<tr>
<td>Reduces repeating information</td>
<td>50</td>
<td>24%</td>
<td>Would reduce the need to tell multiple healthcare professionals same information</td>
</tr>
<tr>
<td>Support choice</td>
<td>8</td>
<td>4%</td>
<td>Would help choices to be supported as the midwife would have built a relationship and know history</td>
</tr>
<tr>
<td>Reduces risk of information being lost</td>
<td>3</td>
<td>1%</td>
<td>Information is less likely to be loss in transition between different midwives</td>
</tr>
</tbody>
</table>
Q 3.6 Concerns acted on (Complications) - Patient care and support

There were 190 comments around patient care and these have been broken down into seven sub groups. The most common sub group with 91 (48%) comments was around individuals not feeling like they were listened to and decisions were made without them. 41 (22%) comments were around more general care and support they received and 18 (10%) said they had to push for decisions.

<table>
<thead>
<tr>
<th>Sub Group</th>
<th>No. of comments</th>
<th>%</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not listened to</td>
<td>91</td>
<td>48%</td>
<td>Service users feeling as though decisions were made for them, concerns</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>dismissed by staff as just ‘worrying’ and birth plans being ignored</td>
</tr>
<tr>
<td>Care and support</td>
<td>41</td>
<td>22%</td>
<td>Service users felt care and support for them was still lacking even after</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>talking through their concerns</td>
</tr>
<tr>
<td>Had to push for</td>
<td>18</td>
<td>10%</td>
<td>Service users felt action was only taken only if they were persistent in</td>
</tr>
<tr>
<td>decisions</td>
<td></td>
<td></td>
<td>their requests</td>
</tr>
<tr>
<td>Availability</td>
<td>17</td>
<td>9%</td>
<td>Did not have the opportunity to talk concerns through, decisions were made</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>by professionals</td>
</tr>
<tr>
<td>Timing</td>
<td>12</td>
<td>6%</td>
<td>By the time they received help it was too late and staff not acting on</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>concerns resulting in further complications</td>
</tr>
<tr>
<td>Continuity of care</td>
<td>6</td>
<td>3%</td>
<td>Constantly faced with conflicting opinions and left out of decisions,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>concerns not spoken about and decisions overturned by other doctors</td>
</tr>
<tr>
<td>Information</td>
<td>5</td>
<td>2%</td>
<td>General confusion about the birth and lack of information provided to service</td>
</tr>
</tbody>
</table>
Women want …

• to choose the care that is right for them, their family and their circumstances
• the care to ‘wrap around them’
• to be listened to - about what they want for themselves and their baby
• to be taken seriously when they raise concerns

Personalised care …

… centred on the woman, her baby and her family, based around their needs and their decisions, where they have genuine choice, informed by unbiased information.
Continuity of carer

- “safe care based on a relationship of mutual trust and respect”
- Reduces preterm birth, fetal loss and neonatal death

The Secretary of State for Health said (17.10.16):

“Of course maternity units need to have the right equipment, …but the latest equipment is irrelevant if the warning signs from the woman – the one person who knows better than anyone what’s going on inside her body - are ignored or under-played.

“… it also helps to have continuity of care, so the same midwives look after a mother before, during and after the birth.

“We need to do better here not only to help parents to feel at ease, but also because it has been shown to improve the outcomes for the baby too”.”
Services should be designed …

• … in a way which put women, their babies and their families at the centre.

• Maternity Service Liaison Committees (MSLCs) provide a means of ensuring [that] women and professionals are listened to.

• [The Review team] saw how effective they are when properly supported and led.

_Better Births. NHS England, 2016 (p32)._
## WAYS WE CAN WORK TOGETHER

1. Focus groups
2. Interviews (one to one semi-structured, discovery telephone)
3. Citizen juries/panels
4. Surveys/Questionnaires (postal, online, telephone)
5. Meetings - (Public, closed, one to one)
6. Public consultation
7. Newsletters/letters
8. Notice boards
9. Designing leaflets
10. Producing bulletins
11. Designing posters
12. Creating presentations
13. Presenting at conferences
14. Reports/publications
15. Lectures
16. Fact sheets
17. Case studies
18. Suggestion box
19. Email
20. Texting
21. Phone-calls
22. Open days
23. Displays and exhibitions
24. Festivals and public events
25. Games
26. Workshops
27. World café events
28. Films and video
29. Debates
30. Community champions or ambassadors
31. After action reviews
32. Patient diaries
33. Online discussion groups/forums
34. Virtual readers panel
35. Websites
36. Opinion polls
37. Exit polls
38. Reviews of complaints
39. Co-authorship
40. Open space
41. Social media – Twitter, Facebook, Tumblr, Instagram, flickr, pintrest, youtube
42. Talking mats
43. Journey mapping
44. Using the creative arts, music, arts and crafts, pictures, poetry, creative writing and dance
45. Story telling
46. Role playing and forum theatre
47. Mystery shopper
48. Ask me 3 and answer 3 questions
49. Comment cards
50. Digital stories
51. Dragons den
52. Emotional touch points
53. Observational exercises
54. Talking wall
55. Experience based design

### TRADITIONAL  ↔  CREATIVE
Transforming maternity: you don’t need a super-power - but it does help!

Thank you for listening!
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