AIMS For a better birth...

Maternity services not wanting to listen and gatekeeping the telling of service user experience: a tale from September 2023

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By Jo Dagustun

In 2016 in England, Better Births was published. That report launched a huge programme of work, with good intentions to improve our maternity services. But how far have we come since Better Births? What difference, so far, has Better Births made?

I've been particularly interested in how we have struggled to operationalise the Better Births vision as something against which we can measure progress. That said, I am heartened by work now underway to establish a set of 'patient reported experience measures' (PREM), to help us get a handle - at a national level - on the direction of travel. But I also worry about this initiative. Insight in this area is perhaps not so easily boiled down to a few key indicators, beloved of those ready to draw up the latest dashboard. So one thing I'm sure of is that the PREM initiative will be just one contribution to our job of listening to, understanding and learning from the service user experience.

And in this context, something really interesting happened yesterday, which seems highly relevant to the national debate about improving maternity services, and that key question about our willingness and

ability to solicit, listen and learn from service user feedback.

En route to settling into the tasks I had planned for my morning, I spotted on Facebook an unusual post on a public Maternity Voices Partnership (MVP) page. It was a striking, colourful, large text post. It asked, in big bold lettering, something like this: "what was the worst part of your maternity experience?"

I have been a member, for AIMS, of NHS England's Maternity Transformation Programme Stakeholder Council for the last couple of years. In that role, I'm keenly interested in how we're doing, as a national maternity service, against the vision set out in Better Births (2016). There are many ways to 'test the temperature' on this. Alongside all sorts of national datasets, this sort of direct service user feedback is one.

This question, from that MVP account, was bold. And it 'worked'. It quickly attracted the attention of perhaps ten local service users who each had a story to tell. In a few lines or a chunky paragraph, they each clearly set out their answer to that question.

I truly believe that engaged service users, who are generous enough of their time to offer such feedback on their experiences, are key participants in the job of maternity service improvement. How can we improve if we do not truly hear, if we do not create the spaces in which service users are motivated to speak up? Without doubt, this sort of feedback to the maternity service is gold dust. For me, it is a very helpful prompt in thinking about how far we might have come, or not, in terms of service improvement since Better Births and to reflect on whether all of the myriad improvement initiatives - that each take up precious staff time - are 'hitting the spot'.

When collecting experience data for this purpose, when that experience took place matters, of course. (One of the frustrations for some with the Ockenden Report was that the vignettes, carefully collected, were not dated in this way.) Diligently, then, the person/people behind this local MVP account had come back to the post, asking respondents to indicate the date of their experience. Many did. Some of the responses were shockingly recent.

I have never seen a question on an MVP page generate such positive engagement. Despite the controversial nature of the question, this was a stunningly effective prompt for feedback. And this is such valuable feedback, which we can use, in the maternity service improvement community, to help us identify those 'sticky areas', those parts that service improvement initiatives are failing to reach. And my sense, in taking a very quick look at the responses yesterday, was that they collectively provided some hugely helpful material for reflection and learning, and also that these were unlikely to be purely local issues.

MVPs, via their social media pages, often seek answers to the question of whether service users have any feedback to offer and what service improvements they would like to see. Recently, on another MVP page, I noticed that service users had been invited to share positive experiences of the local maternity services. I will admit that I popped through a query to that MVP: is this really the best way to signal to service users that all feedback counts, especially to those who may not categorise their feedback as positive? In

my experience, having dabbled in qualitative research and listened to women tell me about their birth experiences in that context, I am certain that these experiences are complex. Listen for long enough, and they are fascinatingly messy stories, with both 'positive' and 'negative' recollections of the maternity services all bundled up into the mix. But that complexity can take time to be told and will only be told if the conditions are right.

Often, the learning for the maternity services from patient experience lies buried. Certainly, simple surveys asking women to rate their experience fall far short, in my view, of capturing the data we need for service improvement. Indeed, I'd argue that it is nigh impossible to make any meaningful sense from them. In that context, the question posed by this MVP - from a service improvement perspective - has worked really well to collect feedback that we need to hear. Put to work, it has proved itself as a question of worth.

But as well as responses from service users to the question posed, there were inevitably other responses which challenged the MVP's action. I'm not sure who these responses were from. Maybe some were from staff members, or from those with family members who worked in the local service. I get it: it's hard to see that 'worst experience' question being asked, and to then see the responses to that question coming in.

And then, perhaps the inevitable happened. When I went back to look in more detail at the thread, that evening, I couldn't find it. I assume it had been deleted or at least set to temporarily semi-unpublished. I have no idea who was behind that decision. I very much 'hope and pray' that it was not senior hospital managers, exerting their power in the name of reputation management.

Let's be clear then, this is only a partial telling of the story. Those involved will have more to say. Whether they do talk about this publicly, and offer their reflections as I have done here, is as yet unclear. But one thing is clear to me. We all know that we have a huge problem across our maternity services in terms of quality and safety. We all agree that it is vital to listen to service users. But at the same time – and here's the conundrum - we are deeply uncomfortable when service users do speak up about their experiences, especially in a public forum. And that's why I believe that this story, in September 2023, is an important indicator of that collective discomfort. It tells us, quite powerfully, of what happens when we do speak up, when we do encourage others to speak up. We are reprimanded. At the click of a button, the service user's voice (which always entails some degree of emotional labour) can be simply deleted by those with power from the public record. If I was one of those service users, whose feedback had been deleted, I would be angry. Very angry indeed. It is wholly inappropriate for an MVP to 'share power with us' on their platforms and then unilaterally, at the press of a button, take away our power to speak. (I am assuming here that the MVP page didn't seek permission from contributors to the thread to delete their text from the public record.)

And maybe it's time for service users to get angry, actually. Not just those who have suffered the very worst outcomes, who are doing a stunning job at present in trying to hold senior leaders to account for maternity service failings. My sense is that service improvement lessons can be learnt from deep

listening to any and all service user experiences, whether that service user has been persuaded to define their experience overall as positive or negative. And maybe we all need to be just a bit more angry that those lessons aren't being learnt. Maybe too we need to work harder to create our own spaces, where we have the power to put what we want on the public record. The AIMS Journal, of course, has played that role over the years. Initiatives such as They said to me are also crucial as we repeatedly contest who has the right to be heard and what stories are 'allowed' to be told and shared.

Feeding back to a system that has hurt us in some way is hard. When we speak, it is the system's responsibility to listen and listen hard. Bravo that local MVP for finding a way that helped some of us find our voice and speak up. Despite my alarm at what happened yesterday - and maybe the post will reappear/ perhaps it already has - you renewed my hope that the MVP structure we have set up is not always co-opted by the system to mute and sideline any dissent from the corporately approved script.

Author Bio: Jo Dagustun, mum of four, has been an AIMS Volunteer since 2017. Jo is a geographer and civil servant by background, and wrote a PhD on women's birth experiences (Learning to birth, mastering the social practice of birth: conceptualising women as skilful and knowledgeable agents). As well as working with others to understand and improve maternity services in the UK, Jo enjoys tutoring on The Brilliant Club's free to access Scholars Programme and spending time by the sea.

Editor's note: For anyone wishing to give feedback about their care in a way that won't be immediately deleted, consider following the formal complaint route. A formal complaint can reflect the complexity of the experience that Jo describes, by stating the aspects of care that had felt good, those that were lacking (the focus of the complaint), and a brief description of the care that would have felt appropriate - concluding with a clear statement about what you would like to happen as a result of the complaint. These links take you to guidance about how to do this : AIMS, and Birthrights. This procedure can be frustrating and disappointing, but it does get your feelings and experience on record and it has the potential for bringing about change.

If the formal complaint route doesn't appeal, AIMS recently featured an article about an online organisation called Care Opinion, which appears to be a very effective way of ensuring your feedback is heard.