









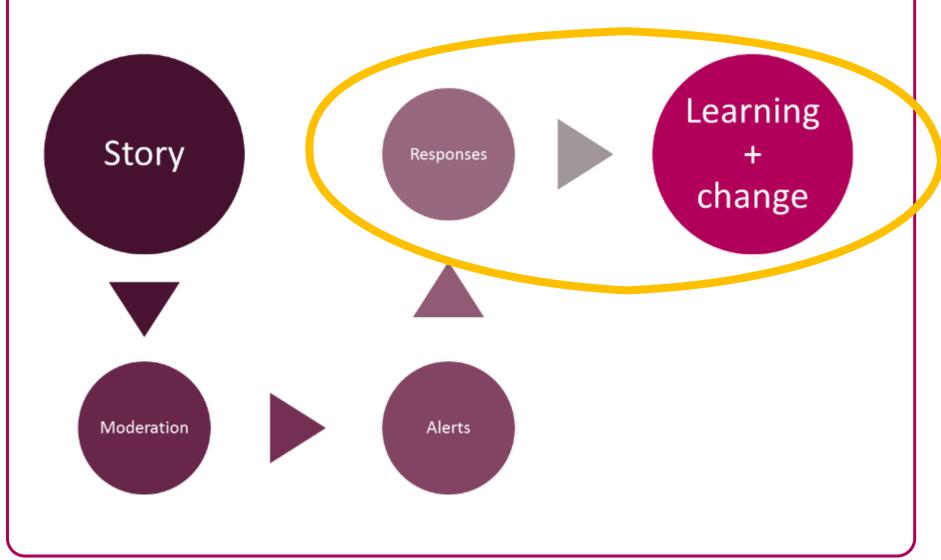
Before we start...

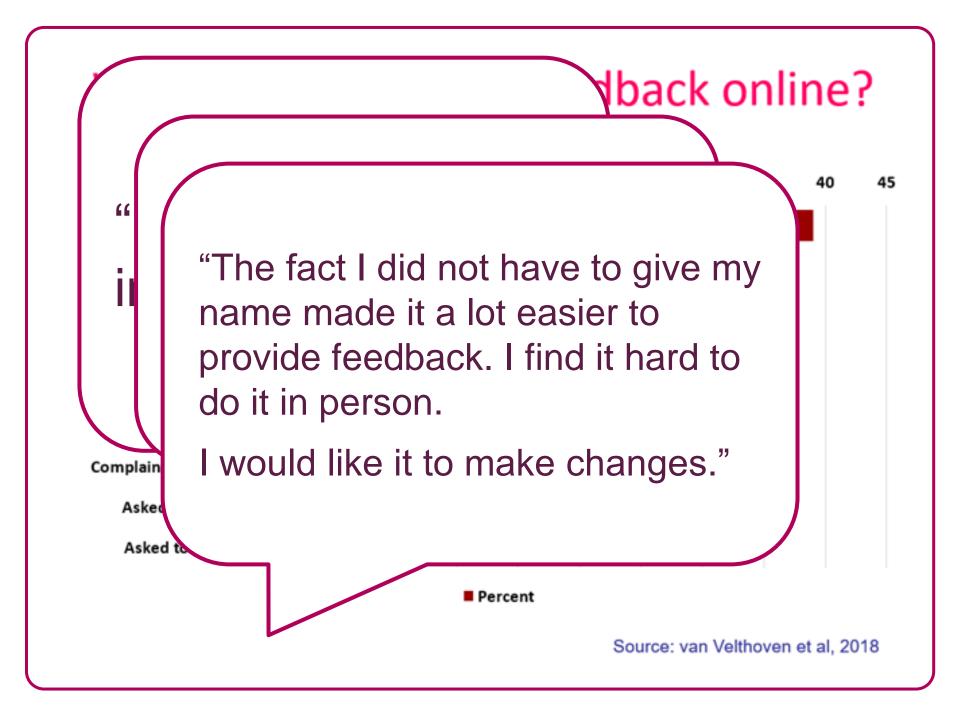
- Recording
- Camera & Mic
- Live Captions
- PowerPoint Live
- Post session email

Today we will look at

- Why do people share feedback?
- What makes a good response?
- My personal experience
- Some other examples
- Final thoughts

Stories – it's about the conversation







Social Science & Medicine

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Caring for care: Online feedback in the context of public healthcare services

Fadhila Mazanderani ^a ♀ ☒, Susan F. Kirkpatrick ^b ☒, Sue Ziebland ^b, Louise Locock ^c,

John Powell ^b

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Abstract

People increasingly provide feedback about healthcare services online. These practices have been lauded for enhancing patient power, choice and control, encouraging greater transparency and accountability, and contributing to healthcare service improvement.

Improving (not complaining about) the NHS

- And I think, when something isn't right, I think it's more about **you just want** them to improve. [INQ23: female, mid-thirties, maternity services]
- [...] unless people speak out and the people who are in an influential position don't know things are happening so, you know, when, where we realise I realise that, you know, the NHS is under such huge demands and everything else but, unless we tell them what's wrong, they can't put things right. [INQ11: female, 60, dementia services]
- The NHS fails, we fail, like we need the NHS to not only survive but to thrive and keep going and any feedback, certainly I'm giving and I know a lot of people in my position are, it's constructive, not because we're being critical but because need this to work. [INQ16: female, mid-thirties, multiple long term conditions]
- I firmly believe that in a subtle and perhaps longer term way, I am contributing to change. [INQ19: female, early thirties, mental health]





Responding effectively to adult mental health patient feedback in an online environment: A coproduced framework

Rebecca Baines MSc X, John Donovan, Sam Regan de Bere PhD, Julian Archer PhD, Ray Jones PhD

First published: 06 April 2018 | https://doi.org/10.1111/hex.12682 | Citations: 11









Abstract

Background

Responding to online patient feedback is considered integral to patient safety and quality improvement. However, guidance on how to respond effectively is limited, with limited attention paid to patient perceptions and reactions.

Objectives

To identify factors considered potentially helpful in enhancing response quality; coproduce a best-practice response framework; and quality-appraise existing responses.

Design

Themes:

Introductions:

"It's hard to forge a trustful relationship with someone without knowing their name" (participant 3), "standard good manners" (Participant 1)

Pictures:

"That's nice, she's put a face to a name, nice smile, looks friendly, not like she's going to jump down your throat in uniform" (Participant 6)

· Identification and explanations of role:

Important due to complexity of healthcare service

Thanks and apologies:

Recognition of time spent providing stories, empowering staff members, boost morale

· Tailoring content:

"The last thing you appreciate is a standard response, you want to be treated as an individual, given an individual response" (Participant4), patients are quick to detect "standardised" or "meaningless" responses. "It's a couldn't care less response. In my tray and out again, makes you question what's the point, it's not going anywhere?" (Participant 5)

Good practice in responding

· Your name, role and responsibilities About you · Your picture · Why you in particular are responding · Within 7 days at most Speed · If slower, apologise and explain why · Personal and specific . Thank author for feedback Content · Apology and offer of help as needed · Offer of follow up if wanted · Other relevant services, with contact details, times and Signposting a named person Offer more than one way to contact a service · Polite and personal Sign-off · Would you be satisfied receiving this response?

https://www.careopinion.org.uk/blogposts/813/how-do-i-respond-well-to-stories

Personal (to Sarah!) inspiration outside of healthcare research

The point of listening is to **truly understand and show you get what the person is saying.** You don't need to see things the same way, or come round to agreeing with them. Rather, you are open to the fact that they might see things differently to the way you do, and you are able to **be moved by their suffering**

Being heard is likely to put the other person in a better frame to hear you.

Both from: Meg-John Barker, Rewriting the rules: An anti self-help guide to love, sex and relationships (second edition)

My own experience of responding

About: Care Opinion



Thank you for printing my story, unfortunately whoever rewrote it omitted the dates I included, which has made the rejigged story read all wrong. If you reread my original story whoever rewrote it will see that for themselves.



This has made the timing in your rewritten story completely wrong, so once the reply's are printed regarding the timing who is going to own up and correct the mistakes?

Maybe before printing you should let the storyteller read your proof before printing.

Even though I am not happy in the way you rewrote my story I still think Care Opinion is a fantastic idea and I wish I had found it years ago.

I wait to see the outcome.

Kind regards

My own experience of responding

How I felt immediately

- Upset this person was unhappy when we strive to provide a good service
- Conflicted because I believe we have a high quality of moderation
- Annoyed this person didn't read the info we provide about why we moderate

However, I knew a defensive response would not help this person feel better (in fact they still liked CO so I didn't want to make things worse), it would not help Care Opinion's reputation either, we need to be open to feedback.

My aim was to repair the relationship, not prove who was right

What I did before responding

- Looked at the story edits for this person
- Looked at our process for how we tell people we edit stories
- Looked at the information we share about editing
- Identified a forum to raise with staff in a non-blaming way
- Asked a colleague to be an objective proof reader



Dear

(A))

Thank you for getting in touch. My name is Sarah and I am one of the senior moderators at Care Opinion. We published your feedback about us on our website so we can reply publicly to you. We encourage Health and Care services to be open and

transparent with feedback, so it is important that we are too.

Firstly, I want to thank you for your kind words about Care Opinion as a platform. We are a small but committed team and it means a lot to us when people tell us they like what we are doing.

I also wanted to address your comments about our moderating. I am sorry that when we removed the dates from your story that it confused the timeline of events. We remove dates from stories to protect the identities of patients and staff. All feedback should be anonymous and we also do not want staff to be identified negatively. This is written in our moderation principles that we display on the site and, in our moderation policy and guidelines for moderators. Our aim is to always ensue the original meaning in a story and I sorry this was not the case in this instance.

When we email story tellers about their story we say "If we can, we publish your story just as you wrote it. Sometimes we have to edit stories a little bit so that we can publish them. We explain why we sometimes do this in our moderation principles". We include a link to the moderation principles.

This means we only email people if we have to make very large edits to stories. We don't usually consider removing dates from stories to be large edit, as we hope we can do this easily without affecting the meaning of the story.

I would like to suggest a couple of options that could hopefully put this situation right for you:

- 1: I can add a reply to your original story to say we had to remove some dates. The NHS organisation and public site users will be able to see this. Or...
- 2: if you would like to suggest an edited version of your story without the dates, that you are happy with we can upload this instead.

- Introduce myself and why I am responding
- Thanking the author acknowledging good
 - Addressing each critical point why did the thing happen that way/how it
- should happen? then followed by how I could "put it right"

Notice there is no "sorry YOU FEEL it is confusing with the dates removed". It's "Sorry IT IS confusing"

If you would like to do the second option you can email me your preferred version at info@careopinion.org.uk and address it to "Sarah".

Thinking more generally about your feedback and how we can continue to improve on the services we provide, I will raise your comments at our monthly moderation meeting. The next meeting is at the start of August. This will allow us the space as a team to think about how we can better moderate people's stories, and how we can keep them properly informed about what we need to do to be able to display their stories on Care Opinion.

I hope my reply goes someway to resolving the issues you have with us and thank you for advocating for other story tellers.

I look forward to hearing from you,

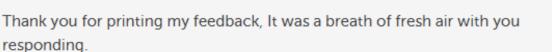
Sarah

2 people think this response is helpful

Was this response helpful? Yes | No

Update posted by Wisteria (a parent/guardian) 2 years ago

Dear Sarah



My apologies I never thought about the issues regarding the dates.

With thanks

Wisteria

After addressing how to solve the immediate problem. I then talk about how we can use the feedback generally

Reply well received because I apologized first. People often need the apology to then be able to move forward

In this example I wasn't able to change our practice very much immediately. Though this did start a piece of work around supporting moderators to think about skillfully editing sentences and staff are supported by regular audits and feedback.

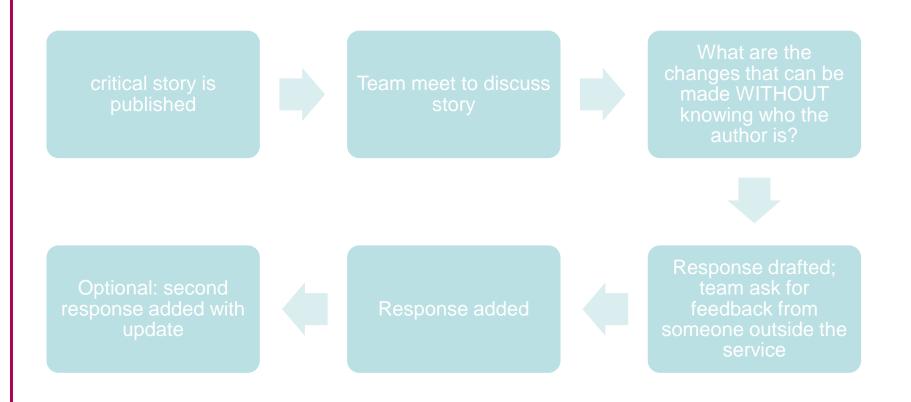
I also didn't re edit the story for the author.

BUT the author was happy. She felt listened to and appreciated the time we took to explain the process. This process seems obvious to us but is clearly not to some of our authors

What are the general points from my example:

- 1. Introduce yourself
- 2. Acknowledge each point in the feedback ask for help identifying these if this is tricky for you
- 3. Apologise sincerely even if you cannot change anything. Even if it feels hard. Often the story author is much more open to your explanations after this. It's the start of repairing the relationship for both sides.
- 4. Try to keep as much as the conversation online where possible
- 5. Do you really need more information from the author? Think how asking them to contact you feels to them when they have already given you so much.
- 6. Explain what you have done with the feedback, even if it seems trivial to you. E.g it was read out and discussed at a staff meeting.
- 7. Remember people's motivations for sharing

Responding to a critical story workflow

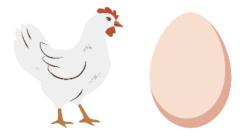


You cannot respond well if your team is not open to feedback

Responding is only half the story. How does you team:

- Receive feedback? Is it welcome or unwelcome?
- Feel about feedback? Does it feel like a gift or an attack?
- Act on feedback? Is feedback used to improve experiences of patients and staff?

And how is your team supported by management and the culture of your organisation?



[Care Opinion] allowed us to have much less guarded conversations with patients that felt much less adversarial and complaint driven. It felt as if the number of complaints reduced.

When we started using CO we had a push on opening ourselves up to feedback. Now five years on, Care Opinion stories and responding to them has become business as usual. It is embedded in our culture to be open and have honest conversations happening between staff and patients

Dr Ben Mearns
Consultant Physician & Chief of Medicine
Surrey & Sussex Healthcare NHS Trust

Making a change without knowing who the author (or staff member involved) is...

"Perfume on neonatal unit"



About: Aberdeen Maternity Hospital / Neonatal Unit (Special Care Baby Unit)

Posted by Caryn (as a parent/guardian), 5 years ago

While I recognise the amazing work that staff in the neonatal, it's disappointing when you arrive for a cuddle with your baby and find they smell like one of the nurses very overpowering perfume! Surely they should not be allowed to wear to such heavy perfumes round these little babies?



neonatal





Response from Nicole Bauwens, Nurse Manager, Neonatal (Children's Division), NHS Grampian 5 years ago • We have made a change



Dear Caryn, thank you so much for taking the time to bring this to my attention.



Sensory stimulation including smell are so important for our vulnerable babies and perfume is not an appropriate stimulant. I will discuss this with the clinical team and can reassure you that

practice has changed from today - clinical staff will no longer wear any perfume to work.

Without feedback, nothing would progress or change within my service.

Feedback is so vital, thank you for advocating as a parent for your baby.

18 people think this response is helpful

Was this response helpful? Yes | No

Making a change without knowing who the author (or staff member involved) is...

- Could this have happened to anyone in your service?
- Can you look at the story from a quality improvement angle rather than looking at it as an isolated issue
- Does it echo other feedback from patients or concerns raised by staff?
- You often get a sense from the story about if the author is sharing the feedback to prevent it happening to others or if that have a specific issue that needs responding to.

Occasionally discussions can happen offline. Agree with the author to update their story

"Birth trauma as a result of poor care at several stages "

About: Adult Mental Health Services / Perinatal Mental Health Team Queen Elizabeth University Hospital Glasgow / Maternity care (Wards 47, 48 & 50) Queen Elizabeth University Hospital Glasgow / Neonatal Unit

Posted by Hazel36 (as a service user), 2 months ago

In December 2021, I gave birth to my first son. I had planned a home birth, but knew that as a primiparous mother I was likely to need a hospital transfer. Because I had a history of depression and PTSD, and already had a couple of bad experiences with this hospital, I focused a lot on being informed about different interventions and maintaining a sense of calm.

My waters went early and my labour was predictably slightly chaotic, which didn't worry me but meant that I had to be in and out of Maternity Assessment for monitoring over 48 hours. On one occasion the doctors on duty were so focused on getting a clear 20 minutes worth of data for my child that they would not let me off the machine to use the toilet, and my partner had to insist. I was contracting while this was happening.

After returning home from this visit I found meconium in my waters, so we went back, and this was when things took a real turn for me.

The doctor in triage examined me and performed a sweep without my consent, something I am still struggling to make sense of because my waters had broken long before.

Story summary				
What was good?				
compassionate EMDR family room				
home birth hon	rth home birth team midwife			
midwives neonatal team NICU				
paediatrician team				
What could be improved?				
anaesthetic blo	od loss			
breastfeeding support consent doctor				
episiotomy infection lost sample				
maternity care no follow up				
postpartum care	scar	sweep		
ventouse				



Response from Gaynor Bird, Interim Lead Midwife, Maternity, NHSGGC 2 months ago



Dear Hazel36,



Thank you so much for taking the time to tell us about your birth experience at the Queen Elizabeth University Hospital. I am sorry to hear that your journey was so difficult and that you had treatment that you did not consent to in Maternity

Assessment. We always aim to ensure that our care is person centred and that any care or decisions are carried out in partnership with women and I apologise that this did not happen.

I am glad that the midwife caring for you in labour was excellent and kind but it is sad that your birth was not as you would have wanted and that your baby needed additional care in the Neonatal unit and it is good to hear how wonderful the staff were.

It is very disheartening to hear how you did not receive the support which we would aim to provide for all women on the postnatal ward, particularly breastfeeding support and I am so sorry that this had such a negative impact on your first few days with your baby.

I am sorry that no-one took the time to discuss your baby's jaundice with you and support you during the treatment journey and that you had such a negative experience. It is reassuring that the home birth team were incredibly supportive and that you found empathy within the neonatal team on your admission to a family room.

In order for us to learn from your journey and shape and improve our service and care as a result of this feedback, can I offer you an opportunity to meet to discuss your journey in more detail? This would be invaluable to the service to help to improve care for all women and their babies.

Kindest wishes

Gaynor

gaynor.bird@ggc.scot.nhs.uk

Initial response

Apology

Acknowledging good and critical feedback

Offer to learn and improve through discussion

Follow up response



Response from Gaynor Bird, Interim Lead Midwife, Maternity, NHSGGC 2 months ago We have made a change



Dear Hazel36,



It was lovely to meet you yesterday and thank you for your feedback. It was great to explore your journey and be able to update you with our actions following your initial post and talk to you about some of the work we have ongoing within QEUH

around Person Centred Visiting, birth choices and our MNPI service. Following our meeting, our neonatal team have shared Quality Improvement work which is in progress to help with ensuring that families have information about their baby and jaundice.

Also, thanks for agreeing to participate in further work we plan to do as part of our Maternity Voices Partnership.

Best wishes

Gaynor

2 people think this response is helpful

Was this response helpful? Yes | No

Notes on these responses

- Notice the first responses doesn't just give contact details. Gaynor
 provides a compassionate detailed response to the points she could
 address... there are often more than you think
- This openness more than likely made the author confident to reach out. They could see Gaynor was not trying to "silence" them by taking the discussion of line
- If the author does contact you, agree an update to add on the site with keep points and changes. Keep the person anonymous.
- If the author doesn't contact you, don't be disheartened. Think back to the reasons people give anonymous feedback. It might be too hard for them emotionally. Please don't waste their gift, it can still be used for improvement (see slide 23)

