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RESEARCH

"Why Should Anyone Want to Make Things Better for me Particularly?" – A Qualitative Exploration of Care Opinion and NHS Care Improvements

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ABSTRACT

Care Opinion is an online platform which enables people to share anonymous feedback (known as "stories") about their experiences of UK healthcare. In Scotland, this platform has official government backing, though healthcare organisations are not obliged to use it. Care Opinion staff review and edit these stories, acting as moderators. Healthcare staff are invited to respond to stories and are encouraged to use it for healthcare improvement. However, the number of changes made and registered on the platform is relatively small. This paper brings together findings from interviews with story authors (those sharing experiences), NHS staff and Care Opinion moderators to explore their experiences of online feedback and its use for improvement. In-depth semi-structured interviews were undertaken with 10 NHS staff, 10 authors and 6 moderators during 2022. The interviews were based on a sample of Care Opinion stories about services from two National Health Service Scotland organisations. Transcripts were analysed thematically. The findings demonstrate the emotional impact for those involved in online patient feedback. Stories add to a growing online repository, which Care Opinion uses to encourage improvement. As our participants highlight, changes and impact from feedback can be indirect. Online feedback can be used in different formats for different purposes. The external platform captures stories which may have been missed. However, change relies on the engagement of healthcare staff.

Keywords: Patient feedback, Quality improvement, Patient experience

1. Introduction

Healthcare services use various methods to collect feedback from patients and service users. These methods can include national and hospital-level surveys to thank you cards and complaints, and in England, the Friends and Family Test.[1] The volume of feedback collected can be considerable for staff to manage and as reported by previous research, often energies appear to be spent on collecting feedback rather than a focus on how it can be used.[2,3] Narrative or qualitative feedback can also be a particular challenge for staff to harness.[3,4]

Online patient feedback is an increasingly common method for service users to express their views and read about the experiences of others.[5] This can range from online websites with links to healthcare services such as Care Opinion and NHS choices, to patient-initiated feedback through online blogs and social media posts.[6] Previous research has explored the characterisation of online feedback and suggested that where the feedback is sought/unsought (was it searched for and used or not), solicited/unsolicited (was the feedback initiated by healthcare staff/organisations or not) and sanctioned/unsanctioned (did the feedback come through

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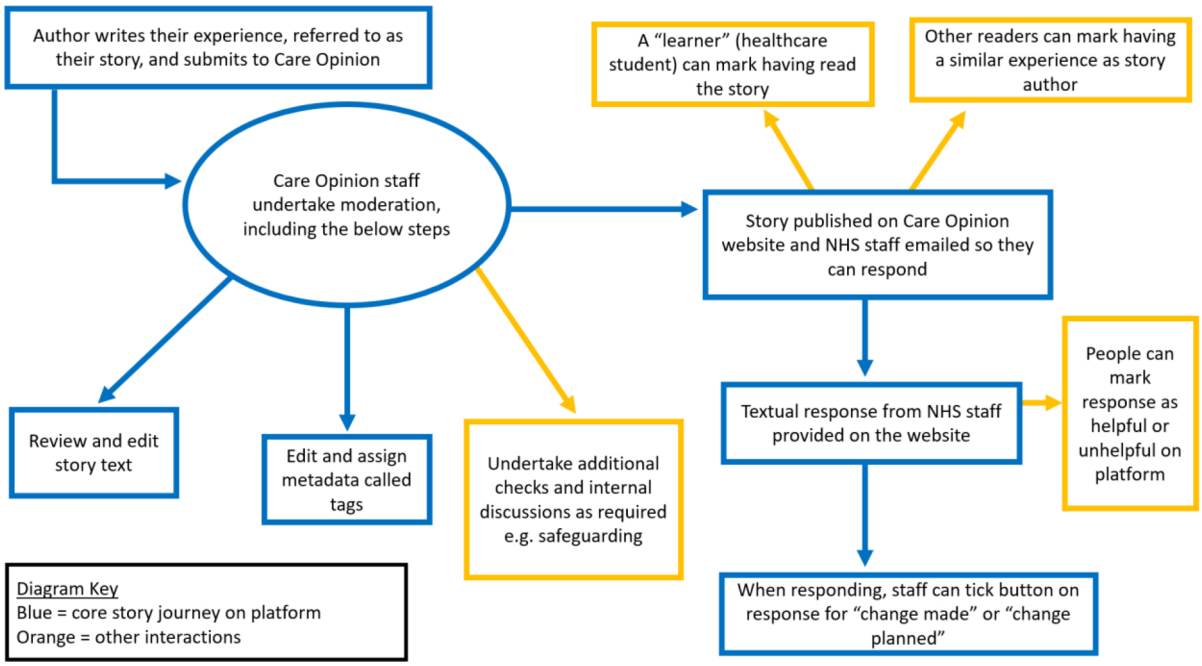

Fig. 1. Care Opinion publication process. This figure outlines key steps in publishing care opinion stories, and other interactions which can occur around this.

an approved channel or not) may influence how it is received by healthcare staff and used for improvements.[7] Yet these categorisations are not fixed for each online feedback method and may be influenced by context, one such example is the difference in government support for Care Opinion in NHS Scotland and England meaning it may be considered sanctioned in Scotland but not in England.

Care Opinion is a social enterprise in the UK which invites patients and carers to share anonymous feedback online about their experiences of healthcare (called "stories"). In Scotland, Care Opinion has government backing and funding, but healthcare organisations are not obliged to use it. In England, Care Opinion has no formal support at government level, but the individual organisations decide whether to engage with it.

Stories are moderated before publication on their website[8,9] and once published, National Health Service (NHS) staff are invited to respond to the story (process outlined in Fig. 1). Previous research has highlighted that patient feedback is often not used to facilitate improvement, particularly if it is not directly solicited by the organisation.[7–10]

Staff responding to stories can flag where it has led to improvements, using the Care Opinion "change made" or "change planned" function.[11,12]. However, research to date highlights that very few changes are flagged on the system – one study found 2 recorded changes from the 77 stories analysed from one Scottish hospital[11], and another found only one change reported from 48 stories from one NHS Scotland Board.[12] Similarly, a study in an NHS England Trust found 1.6% of stories in their sample were marked on Care Opinion as having led to change.[13] However, this mechanism may not accurately capture the impact of stories, as NHS staff may not routinely report changes on the system, or may not regard small differences as a noteworthy change. Similarly, indirect, slower changes could be difficult to identify.[8] Additionally, staff and organisational motivations for, and experiences of, engagement with Care Opinion within Scotland can vary considerably, and building engagement with the platform has been reported as a "long and slow process".[8]

Care Opinion staff undertake different forms of work related to story moderation.[8] Of particular interest is their boundary spanning role as mediators, whereby they work between story authors and NHS staff to encourage staff engagement with the stories, amplifying service users' voices and encouraging service improvement in response to feedback.

Table 1. Overview of interview approaches for the 3 participant groups.

Participant group	Author	NHS Staff	Moderators
Recruitment criteria	Involved in care experience on Care Opinion in one of 2 NHS boards	Responded to CO story based at one of the 2 sites	Moderated story involved in NHS staff or author interview
Example question areas included in topic guide	• Experience of feedback • Emotional experience of feedback • Impact on care from providing feedback	• Use of online feedback in work • Role of Care Opinion is wider feedback landscape • Approaches to responding	• Decision making in moderation • Impact or changes resulting from the Care Opinion story

Although the topic guide focussed on the Care Opinion story example, wider conversations evolved about other related experiences in receiving care, or in work, occurred across the 3 groups.

The research presented in this paper explores different forms improvements can take, the unseen work involved with online patient feedback and how Care Opinion can facilitate change.

2. Methods

In-depth semi-structured interviews were undertaken with 10 NHS staff (mostly in nursing or quality improvement), 10 Care Opinion authors and 6 moderators as part of case study research with two NHS Scotland boards during 2022. The interviews were based around a sample of stories from the boards, selected from the Care Opinion platform. Interviews with NHS staff and authors each discussed one example story. Together, moderator interviews covered 9 example stories – some moderators worked on several stories. Table 1 discusses interview approach. Interviews were audio-recorded and transcribed.

We undertook an inductive thematic analysis.[14] This involved the stages of immersion, familiarisation, establishing codes and creating a coding framework which was applied to the transcripts. EB led the analysis, discussing and refining the codes with LL, MKC and ZS. NVivo 12 was used for data management. The project had input from a stakeholder group with representation from Care Opinion, Scottish Government, NHS board and a patient partner. They helped with the planning of the study and were invited to aid with the analysis. This research was approved by University Medical School Ethics Board (CERB/2021/4/2091).

Example stories were purposively selected to prompt discussion about a range of Care Opinion stories and responses. This included stories about positive, negative or mixed experiences. Table 2 provides an overview of story content, and which participant group discussed them. Quotations are identified with story letter and the participant group, but individual identifiers are not used to protect participant anonymity.

3. Findings

3.1. Emotional labour in online feedback

Authors talked about the emotional effort involved in writing their stories on Care Opinion. When trying to process their experiences, some authors noted speaking to family, friends or others about it. One author described that writing feedback took "*quite a lot of nerve to do it*", particularly when it was a negative experience. Given this, it might take some time before they felt ready to share their experience. One author discussed feeling nervous about providing feedback, as they did not feel they would be listened to.

> *"I was really nervous because I wasn't even going to write anything because I just thought well this just must happen all the time like. I'd already felt like I'd wasted people's time. . . and I just thought well, why would anyone really want to reply, it's not really like, I'm just one person. I'm nothing special. Why should anyone want to make things better for me particularly? But then I'm starting to think well actually like why should I be spoken to like that? . . .So, yeah, I did start to get excited because I was like 'oh I wonder what's going to happen?' and I just, I really wanted just someone to acknowledge actually do you know what? It's not just you, it's not okay." (Story A, Author)*

Some authors described writing their stories as "*cathartic*", like "*writing a diary*", particularly after negative experiences. Some discussed naming as many staff as possible in positive stories – as they felt it would boost their morale. Sometimes they decided

Table 2. Overview of Care Opinion stories within sample used for interviews.

Story A	Author interview. Negative experience of midwifery care. Response offered offline discussion.
Story B	Author and moderator interview. Mostly positive birth experience and thanks but suggestions for improvements were made. Response said they would share thanks with staff involved and take suggested improvements on board but no further details.
Story C	Author and moderator interview. Complaint about relative's treatment. Responder offered to discuss offline, author responded online. Another person marked having had a similar experience through an option on the Care Opinion platform.
Story D	Author and moderator interview. Negative experience around gynaecology issue and staff communication. Response offered to discuss offline. Another person marked having had a similar experience through the Care Opinion platform. Story also noted as having a learner read it.
Story E	Author and NHS staff interview. Complaint about communication systems. Multiple responses on platform. Another person marked having had a similar experience through an option on the Care Opinion platform.
Story F	Author interview. Mostly positive experience of urgent treatment for leg but suggestions for improvement made in story. Response said they would share comments about improvements, but no further information provided.
Story G	Author interview. Positive experience of long-term illness treatment. Two staff responses from different services involved in the story. Both responses appreciative and one advised they would share feedback with teams.
Story H	Author interview. Complaint about ongoing medical issue and long wait for surgery. Response offered contact number to get in touch offline.
Story I	Author interview. Positive experience of fracture care. Response said the positive feedback would be shared with the team.
Story J	Author and moderator interview. Compliment on gardens at hospital. Response was appreciative and advised they would share feedback with relevant teams. Others marked having had a similar experience through an option on the Care Opinion platform.
Story K	Moderator and NHS staff interview. Mixed experience story highlighting treatment delays. Response invited offline conversation. Author replied back while at hospital to highlight ongoing issue. Further staff response indicated conversation taken offline.
Story L	Moderator and NHS staff interview. Positive experience saying thanks for relative's care (oncology). Response indicated they would share feedback with team. Several people marked response as helpful.
Story M	Moderator and NHS staff interview. Positive experience saying thanks for care (urology). Response advised staff would be grateful for feedback. One person marked response as helpful.
Story N	Moderator and NHS staff interview. Positive experience saying thanks to staff but hints at improvement needed for one of the two sites involved (oncology). Several responses thanking for feedback and advised would share with the team. One response invited further discussion offline.
Story O	Moderator and NHS staff interview. Negative experience of staff communication and accessing wheelchair. Several responses which encourage discussion to be taken offline.
Story P	NHS staff interview. Mixed experience of child's appointment being cancelled last minute but staff providing alternative appointment quickly. Response stated feedback was shared with team. One learner read the story.
Story Q	NHS staff interview. Positive feedback on maternity care. Response advised they would share feedback with staff.
Story R	NHS staff interview. Mixed feedback on surgery care. Compliments staff at time of surgery but critical of aftercare and results delay. Response invited discussion offline. One person marked having a similar experience on Care Opinion.
Story S	NHS staff interview. Negative experience of partner's care. Critical of arranging blood tests needed and receptionist communication. Several NHS responses. First response indicated feedback shared with team but generally all NHS responses invited further conversation offline. Last response indicates discussion taken offline. Several people marked some responses as helpful. One person marked having a similar experience as author on the Care Opinion story.

to include additional elements of praise to balance any negative comments – in the hope staff might listen more.

Authors shared a range of reasons for wanting to share feedback. Some wanted to provide a public thank you or wanted staff to see their thanks for caring for them. Others wanted a change in their own care, whether that was to be seen quicker or get help when they did not know who to contact. Several wanted their feedback to improve things for other patients in future.

Almost all authors wanted a response from the service, as a demonstration that staff were listening. One who shared negative feedback highlighted that the time waiting for a response was frustrating and they kept checking their emails in hopes they would hear back. This demonstrates the psychological and emotional energy spent on the feedback process. Some talked about how if patients had put time and energy into providing feedback, not having a response, or having a poor response was disappointing.

> *"All I can think if I spend a lot of time and I give a lot of thought to it before I shove something in, and sometimes it's fairly frustrating because the answer you get is. . . well*

one particular one was just nonsense, just not worth the pain" (Story J, Author)

It was noted by participants that many responses to negative feedback followed similar patterns. These often involved asking the author to get in touch offline (e.g. email, telephone). Some authors stressed that they did not want to get in touch with the service offline and discussed the importance of anonymity when providing feedback. For those who shared positive experiences, anonymity was less of a concern. Some authors worried that sharing negative feedback could have repercussions for ongoing care, particularly if a member of staff knew who had provided critical feedback. One talked about negative feedback provided on a family member's care, which they believed impacted future care. Although this feedback was not via Care Opinion, it demonstrated that for those who receive longer-term care there was a real concern about providing identifiable feedback.

"And he does not like to rock the boat. He will ask and he does question it, but he doesn't get the answer he wants, or they quickly answer, he says, "I don't want to rock the boat," because on previous occasions, he felt it impacted on the subsequent care." (Story C, Author)

NHS staff also discussed the emotions of working with online patient feedback and their fears about responding online. Some reflected that replying on a public forum could be daunting. NHS staff talked about how it could be emotional discussing stories with their staff. This could be the pride from sharing positive feedback as well as an emotional response to receiving negative feedback. It was reported that staff wanted patients to have a good experience, and participants found it upsetting or frustrating where this was not the case, as demonstrated below.

"Disappointed in the staff, in our services, that we hadn't got it right for this family. . .. it is not how I see services to be delivered. . . I do think the family were entirely reasonable to give us feedback that says, "You've done this, and because of your actions, it's impacted on us in this way"" (Story P, NHS Staff)

Some NHS staff also commented on how the impact of negative feedback could be considerable: "*it can be crippling for teams*". They described being fearful of the public nature of feedback and their response. Some participants shared experiences of inviting authors offline to discuss feedback. There was less trust in the validity of the "anonymous" concern (even though some authors were identifiable from their story) than something which was verified through their formal complaints systems, as the following highlights.

"I mean, obviously, with Care Opinion, the negative, there's no names if it's a negative thing, but the senior charge nurse may or may not be able to look at something and have an idea who is being spoken about and might then have an individual conversation with that person. But that's really about as far as it goes. It's not given the same gravitas as feedback that comes through the feedback system, where it might because that's not anonymous, and you do get names of people. There might be a more thorough investigation into a complaint that comes through the feedback system compared to an anonymous concern that comes through Care Opinion." (Story M, NHS Staff)

3.2. Changes and impact arising from online feedback

There were two stories, from one board, which authors reported had led to direct changes. One participant was able to request a change in healthcare professional, while another felt their surgery was scheduled more quickly as a result of their story. In both cases, the conversations were taken offline, and authors got in touch with staff directly. There was no change marked as planned or made on either story through the Care Opinion platform.

In most stories within our sample, authors and moderators were not aware of any direct change resulting from their feedback, although this was not the only reason authors decided to share feedback. However, among those who wanted a change and did not get it, authors still hoped that sharing experiences would help other future patients in similar positions. Some felt that wider changes or improvements were unlikely to result from individual stories, but that repeated patterns of similar experiences could make staff more likely to listen and use their feedback.

Interviews with NHS staff highlighted the number of perceived demonstrable improvements being made from individual stories and reported on Care Opinion was limited. One clear example was discussed by someone in a senior nursing role. They reported ordering additional resources and sharing this change with the relevant teams who could access these resources as needed. This change was marked on the Care Opinion platform against the original story. However, this was not one of the sample stories but a different one that participants raised during the interview. In a second example, the change planned had not arisen from a single Care Opinion story but was in response to an issue which had been raised several times in different ways. This had prompted staff to monitor the issue internally with the intention of evidencing the need for improvement. Planning this change involved bringing together several professionals and teams. This work was still underway at time of interview and therefore had not been marked on the platform.

In examples where staff felt that improvement was possible, some reported inviting authors to discuss their stories further offline but suggested that a formal complaint was more likely than a Care Opinion story to prompt an active organisational response. In both boards, NHS staff generally did not follow up on stories or make changes if the author did not get back in touch.

Whilst there was limited direct improvement arising from stories discussed with NHS staff, they noted other potential forms of improvement. Staff discussed how feedback was useful for learning and reflecting on service performance. Staff shared how stories allowed them insights on what patients wanted from healthcare experiences and its usefulness for teaching students, which the following quotation highlights. Staff from both sites highlighted how Care Opinion stories were mostly positive. Staff noted that online feedback was particularly important during Covid-19 where in-person thank-yous (e.g. cards) were harder to share with staff. Positive feedback was seen to be valued by staff for boosting morale or use in staff revalidation. However, one noted that learning from positive feedback was challenging for services. Generally, positive feedback was widely shared, and some felt it could help to promote good practice.

> "*. . .It actually helps us to understand what it is the patients want from their experience of healthcare and, in a way, you can actually use that with, for example, students. . . to help them to understand what patients expect, what patients. . . need from services." (Story M, NHS Staff)*

Authors also felt their stories could have a wider impact. They wanted to share the positive care received to counteract negative comments they heard about the NHS in the media. They felt that positives could be "*nice to hear*" for staff and boost morale. One noted that they had been told how feedback could be used for staff appraisals and encouraged others to share positive feedback for this reason. They also suggested that other patients reading the feedback might feel reassured about the care they would receive.

As well as positive feedback being beneficial to staff, some participants described how it could prompt service improvements. For example, there was a positive example story regarding a garden, and its calming effect on the patient. The moderator who worked on this story thought sharing this might help other services see the benefit.

> *"They go into detail about their experience. . . it's just so lovely, and also the fact that they highlighted something outside of their care, so it wasn't part of their care journey necessarily, it wasn't their treatment, it wasn't the staff, it wasn't the transport. It wasn't any of that. It was the scenery of where they were. . . it was a help to them and helped to reduce their anxiety. I thought, also, it would be a good thing to share for other services to see because maybe they're developing a garden, or maybe they're thinking of having a garden nearby, and spreading that awareness that these things really are important for people" (Story J, Moderator)*

For moderators who discussed positive story examples, it was generally felt that a direct change in response to every story was not needed. In contrast they could identify many potential improvements which could be made in response to negative stories, but which rarely featured in staff responses. Moderators discussed how linking multiple stories could allow NHS Boards to build a wider picture. The following quotation explores the different ways feedback could be used at varying levels, although organisation-wide improvement might not be easy to report on Care Opinion in response to single stories.

> *"I'm a big believer that you can learn from anything, but there is a lot here that... in terms of the story that people can learn from, and you can see in almost every line that there's something that can be taken away. There's information here that they're giving them about discharge, there was information here about scans... so there's so many individual things here that we can pick up on. You can actually see lots of these are picked up on in the metadata so - operation, skin, discharge, CT scan... that there are lots of little things that can be taken away, so this can be used to learn from this individual story or other stories like it. What are they saying? Is this one story? For the board, what can we learn by what all patients are telling us?" (Story C, Moderator)*

One NHS staff participant discussed staff requesting Care Opinion feedback reports which could provide insight for planned improvement projects, enabling stories to contribute to organisation-led improvement.

Participants suggested that learning from feedback might be embedded through staff training and could support a shift in culture. It was reported by a moderator that Care Opinion has been involved with training the next generation of healthcare professionals. One author was pleased to see their story had been marked as being viewed by a "*learner*" (a student training as a healthcare professional) and hoped this could help future healthcare professionals learn important people skills.

Although none of the example stories platforming our sample were marked as leading to a change, they could still be impactful. However, for those that did not take their conversations offline, the response on the platform might be the only way they would know whether their feedback had an impact:

> *"I know that the people involved in the cancer stuff were obviously very pleased because you can tell. The person says, "...I passed it all on to everybody", so. And my public thanks one, I just had a look this morning, over 700 people have read that. So, a large number of them will be the people in that particular hospital, but a lot of them, who knows who they are, nobody knows." (Story J, Author)*

3.3. Creating a collective of experiences to enable improvement

Sharing feedback can involve considerable emotional labour. Online patient feedback allowed participants to share experiences which may have been missed or would not fit into the traditional forms of feedback available through the NHS.

One author described how they had turned to the public platform in the hope of action being taken after they felt other forms of feedback they had provided were not dealt with suitably. They mentioned how a member of staff encouraged them to provide feedback in Care Opinion.

> *"I think the only way to highlight this is for it to be put on the Care Opinion line, in fact it was an NHS member of staff that suggested that I do that because she said that's probably the only way that you'll shame them into doing anything." (Story C, Author)*

Some NHS staff shared that they had also used Care Opinion to provide feedback on their own experiences of care. Some felt that this provided them a safer route to do so due to the anonymity offered, but still faced the limitation of being asked to get in contact offline.

> *"I've put stories on and people have said to me, "Get in touch," and I know my colleagues have also put stories on, and people have said get in touch, and they don't... I guess being a staff member is the reason I wouldn't get in touch because then it's putting myself in a situation that I might feel uncomfortable with. Like, I would like them to know what I felt maybe could be improved on and I would like to see a little bit change come from that, but I don't necessarily want them to know that was from me because then if I meet them in meetings, it's almost like... I've been criticising the staff that I work with. And I guess that's silly because that's exactly what the barrier that Care Opinion are trying to break down, isn't it?" (Reflecting from Story O, NHS Staff)*

Responding to Care Opinion feedback might not only offer a chance for patients to be heard but could

offer a chance to mend relationships and restore trust.

> *"I think that's still relatively unusual in healthcare to see genuine apologies to patients made in public, which is what this is, and so I give extra credit for that. I think that is important and I think it's a powerful recognition for the patient that their concerns have been heard, and I think in itself an apology can be very restorative to a relationship. And in this case, there is a relationship that needs to be restored because the patient has been, you know, as I was saying earlier, their trust in the service has been significantly undermined by their experiences of poor communication." (Story D, Moderator)*

Authors discussed how even with overall positive experiences this platform allowed them to suggest improvements. This was particularly relevant when they felt more complex feedback systems (such as formal complaints) were not worth pursuing. It could be argued that the external setting provides a more neutral location, challenging those traditional power imbalances.

Moderators talked about some of the opportunities the platform provided for patients to connect with others. This could take different forms. For example, it was discussed that others could mark on the platform that they had similar experiences to ones published and this might help patients feel less alone in their experience. The platform allows searches for other experiences of a particular service and might help patients with what they were going through. It was also proposed that seeing others having similar experiences might help others to feel empowered to share their own. This was broadly reflected by authors.

Understanding what is important to patients may be key to ensuring they trust the service and care provided. Moderators highlighted that emotions of the experience could be captured through the relevant word or phrases in the Care Opinion tags (see Fig. 1). It was felt this was as an important element of the experience and relationship between the patient and service as the following quotation captures. The breaking down of traditional power structure and organisational barriers might also be reflected in the more informal responding style of many NHS staff.

> *"I'm just looking at the tags here actually and I notice that we've added or either the moderator or the author has added a number of emotion texts here as well, anxious, misinformed, nervous... I think they're also an important part of the Care Opinion design because it's not just about saying to somebody well you know look we made the right clinical decisions, you're getting better... But it's also about how people are feeling about their care and I think that's really important not just for people's immediate emotional mental health but also for the likelihood... that they're in a relationship of trust with the service that they feel heard, that and we know how important that is in terms of things like returning to the service again, taking medication...but actually, having a good relationship with the...care providers is really important for all of that... I think the question of the emotions for patients is really important and it's, I think it's underemphasised within formal healthcare training." (Story D, Moderator)*

The challenges around internal systems were also reflected in NHS staff interviews. NHS staff explained that they found the Care Opinion reporting functions easy to access in contrast to the internal systems such as formal complaints processes. These systems presented particular difficulty in capturing positive feedback across large organisations. Several NHS staff noted that a focus on only complaints was not sufficient and balancing the negative with positive stories (e.g. from Care Opinion) was important. NHS staff talked about a range of reports which they produced, such as annual reports for Scottish Government or for internal sharing at management meetings. They reported wanting to include positive feedback to highlight what was working well or provide a more well-rounded picture alongside complaint metrics.

> *"...we have a performance review so... we always put in a bit about patient experience. So we always say, "So here's how many complaints we've had" and I always put in, "And here's, you know, some of the compliments we've had," and I use Care Opinion..." (Story L, NHS Staff)*

4. Discussion

Our findings have captured some important perspectives on online patient feedback. Firstly, there is considerable emotional work involved for those who write and respond to online patient feedback. Secondly, there is limited direct change happening from individual stories. However, there were wider examples of change resulting from the sharing of stories. Additionally, even when stories do result in a change, this is not always reported on the Care Opinion website. Finally, the platform Care Opinion enables a collection of experiences including views which would be missed by other methods. The platform design and its external nature aims to encourage NHS organisations to listen, utilise their tools and improve these services.

The emotional work of writing Care Opinion stories and waiting for a response were detailed in our findings. Emotional work or labour can be broadly characterised as that which requires an individual to deal with and manage feelings generated when interacting with others.[15] Our findings resonate with other accounts on the emotional impact of providing patient complaints.[16] This previous research involving NHS service users and staff highlighted the emotional aspects of complaints. The emotional responses around stories were captured in NHS staff who worked with the feedback. Previous research captured the emotions of moderators around Care Opinion stories.[8] This demonstrates a considerable emotional labour for these groups involved with online patient feedback, and that these unseen efforts should be recognised and supported for enabling care improvement.

Authors described how when writing their stories, they thought carefully about what to include. This was seen in other research, who found that their participants did not want to be seen as "*moaners*" and had fears about being seen as a serial complainer.[17] This reflects our findings, but authors added that they intentionally included positive elements in their stories, so it was more palatable to staff. Some authors shared that writing down these experiences was cathartic. This was also reflected by moderators in previous Care Opinion research who noted some authors may share their experience to mark the end their journey or experience.[8]

In similarity with previous research[17], our authors needed staff to engage with their feedback for changes to be made. Waiting for the service to respond could have an emotional impact on patients. Even when a response was provided, we found that there could be an expectation of conversations offline or multiple instances of sharing feedback to motivate change. This required considerable work from the authors to make sure their voice was heard. Others have reported on the tendency of NHS staff in Scotland to take conversations offline from Care Opinion stories.[11] Similarly to our own findings, they highlighted how staff felt uncomfortable with the anonymity of patients on Care Opinion and wanted to "*investigate*" this feedback to explore whether it was truthful. This might speak to a wider mistrust in patient feedback as a source of evidence, particularly when considering single experiences. An Inadmissible Evidence report[18] highlighted how the patient's experience was treated with scepticism, yet staff evidence was believed as fact. They reflected that often inquiry reports into NHS services found patient experience had been "*ignored or suppressed*". However, for some of our participants there was considerable concern about coming "*offline*". This presents the "*anonymity paradox*" – a particular tension of online patient feedback.[19] Whereby, there are benefits of anonymity perceived by patients who shared experiences online, such as a reduced fear of repercussions, but the anonymity of these patients makes the staff feel uneasy. Researchers have highlighted that anonymity might be a motivation for using online feedback over other feedback methods, especially if the patient or family were leaving critical feedback or still receiving treatment at the time of sharing.[19] Yet as our research highlighted, not all online feedback was treated the same. Positive feedback does not undergo the same investigation or suspicions around its truthfulness as negative feedback. Participants shared how positive feedback was less likely to be seen as an opportunity for change or improvement directly. These findings were also reflected in the work of Gillespie and Reader[20] who carried out an analysis of patient compliment letters in English hospitals. They found that these letters offered an opportunity to promote positive behaviours from patient perspectives which could support care improvements, yet they were generally not utilised by the organisations. They also argued how compliments could be used to support staff and reduce burnout which was reflected in our own findings, with participants reporting the morale-boosting role of positive feedback.

Reflective of previous work on soft intelligence and using qualitative feedback – "*aggregation*" of accounts was more likely to prompt action than single experiences.[4] Several participants reflected that more than

one story or experience was more likely to enable change. Creating an accessible repository of experience stories on Care Opinion may enable staff to search for and bring together experiences. This could help those authors who did not want to engage offline and lose their anonymity but want to see a change. However, as reflected in conversations with moderators it may well depend on the kind of change needed.

We captured how some patients and carers had to work through the emotions of processing, writing and sharing their experiences. These authors may have different intentions behind sharing their experiences. For some, sharing on the platform enabled the change they wanted to happen, whereas for others, sharing their experiences adds to a growing collection of healthcare stories which they hope will help others. By bringing these stories together, Care Opinion aims to encourage change and improvement. However, this concept of improvement can be wide – from individual change to cultural shifts – yet capturing any of this on Care Opinion can be challenging.

To our knowledge this research has been the first to capture the views of authors and moderators on Care Opinion stories about NHS Scotland boards. Although the sample size of these groups is small, the interviews provided rich details and adds new knowledge to a growing field. This research has wider national and international relevance, adding to existing research on online patient feedback. It may also interest those exploring emotional labour in patient feedback – which has focussed mainly on patient complaints to date.

Previous research has highlighted that as an online platform, Care Opinion may be limited for those with low-literacy or limited internet access.[12] However, Care Opinion does offer alternative means for these populations to still provide feedback such as by offering picture stories through Talking Mats, language translations and offering immersive reader buttons.[21] However, this may limit the applicability of the findings to the entire population.

Participants from all groups commented on the challenges around existing NHS internal feedback systems. Participants highlighted issues around providing feedback, a focus on complaints, and sharing feedback information. Together this emphasises a need for easily accessible method of feedback and questions who these internal systems are benefiting in their current format. The public nature of Care Opinion prompts a different response by challenging the traditional NHS power structures and the normal handling of complaints internally and privately. It also confronts NHS control over deciding how patients can provide feedback. Moving to an external space, such as through Care Opinion, may create a neutral location for feedback to be shared. Care Opinion could be considered a disruptor of traditional feedback methods as it offers an accessible, public platform held externally from the service, through which patient and staff can communicate. However, NHS staff still have considerable reservations about using online patient feedback, and as our research and others show there was a fear of online responding.[11,12]

5. Conclusion

Our findings highlighted that improvement in response to feedback can take different forms. Online patient feedback, through Care Opinion, offers a collective of experiences which enables a wider range of feedback to be captured and used than the traditional methods held internally by healthcare organisations. It may also overcome the need of some staff to verify and validate individual experiences. However, sharing or working with healthcare feedback is an emotional labour and appropriate support is required.

Conflict of interest

LL took up a non-stipendiary director role at Care Opinion one year after the fieldwork was completed (start date January 2024). There are no other conflicts of interest to acknowledge.

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