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## Caring for Care: Online Feedback in the Context of Public Healthcare Services

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| <b>Abstract:</b>                    | <p>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. Online feedback has also been critiqued for being unrepresentative, spreading inaccurate information, undermining care relations, and jeopardising professional autonomy. Through a thematic analysis of 37 qualitative interviews, this paper explores the relationship between online feedback and care improvement as articulated by healthcare service users (patients and family members) who provided feedback across different online platforms and social media in the UK. Online feedback was framed by interviewees as, ideally, a public and, in many cases, anonymous 'conversation' between service users and healthcare providers. These 'conversations' were thought of not merely as bringing about tangible improvements to healthcare practices, but as in themselves constituting an improvement in care. Vital to this was the premise that providing feedback was an enactment of care – care for other patients, certainly, but also care for healthcare as such and even for healthcare professionals. Ultimately, feedback was understood as an enactment of care for the National Health Service (NHS), as symbolically encompassing all of the above. Putting these findings in dialogue with STS scholarship on care, we argue that, in this context, the provision of online feedback can be understood as a form of care that is, simultaneously, both directed at healthcare (in the round, including patients, professionals, services, organisations, and, of course, health itself) and part of healthcare. We conceptualise this as 'caring for care'. This conceptualisation moves beyond dominant framings of online feedback in terms of 'choice' and 'voice'. It embeds online feedback within pre-existing healthcare systems, relations and moral commitments, foregrounds the mutuality of care relations, and draws attention to the affective labour of feedback practices.</p> |

**Cover Page**

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Online feedback was framed by interviewees as, ideally, a public and, in many cases, anonymous ‘conversation’ between service users and healthcare providers. These ‘conversations’ were thought of not merely as bringing about tangible improvements to healthcare practices, but as *in themselves* constituting an improvement in care. Vital to this was the premise that providing feedback was an *enactment of care* – care for other patients, certainly, but also care for healthcare as such and even for healthcare professionals. Ultimately, feedback was understood as an enactment of care for the National Health Service (NHS), as symbolically encompassing all of the above.

Putting these findings in dialogue with STS scholarship on care, we argue that, in this context, the provision of online feedback ~~needs to~~ can be understood as a *form of care* that is, simultaneously, both *directed at* healthcare (in the round, including patients, professionals, services, organisations, and, of course, health itself) and *part of* healthcare. We conceptualise this as ‘caring for care’. This conceptualisation moves beyond dominant framings of online feedback in terms of ‘choice’ and ‘voice’. It embeds online feedback within pre-existing healthcare systems, relations and moral commitments, foregrounds the mutuality of care relations, and draws attention to the affective labour of feedback practices.

**Keywords:** UK; NHS; Digital Technologies; Care; Online Feedback; Qualitative Interviews.

# 1. INTRODUCTION

Over the past decade, the number of people who go online to rate, review and provide feedback about their healthcare experiences has been slowly and steadily growing (Gao et al., 2012; Greaves and Millett, 2012; van Velthoven et al., 2018). This trend has been met with considerable concern from healthcare professionals, with fears expressed about accuracy and representativeness, as well as implications for care relations and professional (in particular medical) autonomy (McCartney, 2009; Patel et al., 2015; Samora et al., 2016; Menon, 2017; Atherton et al., 2019). At the same time, online feedback promises to enhance patient power, choice and control, encourage greater transparency and accountability, and contribute to healthcare service improvement in a cost effective manner (Greaves et al., 2012; van de Belt et al., 2015; Browne and Shaller, 2018).

Survey research indicates that 42% of UK internet users (n=1824) have read some form of healthcare-related feedback online, while only 8% have provided feedback about their own experiences (van Velthoven et al., 2018). This pattern is consistent with health-related social media use, where the number of people reading about healthcare experiences far outstrips those providing it (Mierlo, 2014). Thus, the feedback practices of a relatively small group has the potential to affect a much wider pool of patients, their family members and healthcare professionals.

A key concern expressed by healthcare professionals, especially doctors, is that online feedback is produced by an unrepresentative minority expressing extreme views and, as such, is of limited value for healthcare improvement (Atherton et al., 2019; Patel et al., 2015).

However, rather than being dominated by disgruntled service users and complaints, much online healthcare-related feedback is positive (Kadry et al., 2011; Lagu et al., 2013; Emmert

1 et al., 2014; Emmert et al., 2015; Greaves et al., 2012; Menon, 2017; Liu et al., 2018; Powell  
2 et al., 2019). This tendency has remained consistent over time, across national healthcare  
3 systems, different medical specialists and feedback platforms (Boylan et al., 2019).  
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9 Despite their central importance to the online feedback landscape, little is known about how  
10 those providing feedback in different healthcare contexts understand their own practices  
11 (Boylan et al., 2019). Drawing on 37 qualitative interviews with people who read (n= 37)  
12 and/or wrote (n=32) online feedback about their own or a family member's experiences of the  
13 National Health Service (NHS) in England (n=34) and Scotland (n=3), this paper analyses  
14 experiences of and motivations for providing online feedback. It focuses on how people who  
15 posted online feedback across different platforms in the UK understood the relationship  
16 between online feedback and care improvement.  
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31 The paper foregrounds four aspects of the relationship between online feedback and care  
32 improvement as articulated by interviewees. One, understandings of how online feedback  
33 might improve healthcare were premised on pre-existing embodied, emotive and, at times  
34 ambivalent, relationships with the NHS. Two, healthcare professionals and services were  
35 positioned as both subjects and beneficiaries of online feedback. Three, a major motivation  
36 for providing feedback was to improve care for other patients and their families, with whom  
37 interviewees felt a strong identification and communality. Fourth, interviewees wanted online  
38 feedback to, ideally, take the form of a two-way 'conversation' between service users and  
39 healthcare providers. Across all four, the public and anonymous nature of online feedback  
40 were foregrounded as crucial facilitators of care improvement.  
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In what follows, we put these findings in dialogue with Science and Technology Studies (STS) work on the ethics of care. Through our analysis we suggest online feedback be understood as a way healthcare service users (patients and their family members) *perform enact care* for other patients and their families, but also, significantly, for healthcare practitioners and services – what we conceptualise as ‘caring for care’. A key way interviewees hoped online feedback could facilitate this particular form of care is through publicly available (often anonymous) digitally mediated feedback ‘conversations’.

Most extant research and health policy has framed online feedback in terms of patient ‘choice’ or ‘voice’, or a conjoining of the two with capturing the patient ‘voice’ seen as a means of enhancing ‘choice’ (Adams, 2010; Powell et al., 2019). We argue that even when modelled on systems used by commercial enterprises, online healthcare feedback cannot be conceptualised as consumerist behaviour aimed at reinforcing patient choice; nor as a means of democratising the technocratic instrument of quality control through harnessing the patient’s voice. Instead, we propose ‘care’ and ‘~~conversation~~conversation’ as alternative framings for understanding online feedback practices in the context of public healthcare systems. This dual conceptualisation foregrounds the mutuality of care relations and highlights the affective labour of feedback practices. Furthermore, it draws attention to two ways online feedback can improve care: first, through prompting tangible changes to healthcare services – online feedback *for* healthcare improvement; second, as a form of care improvement in its own right – feedback *as* healthcare improvement.



## 2. ONLINE HEALTHCARE FEEDBACK: GOING BEYOND 'CHOICE' AND 'VOICE'

Much academic literature on online healthcare-related feedback has come from the US and Germany, but there is a growing body of work in different healthcare systems, including free at point of use systems like the NHS in the UK (Boylan et al., 2019). The link between feedback and patient-consumer choice is, unsurprisingly, a common theme in studies from countries with private healthcare systems, like the US, and in relation to elective procedures such as plastic surgery (Hanauer et al., 2014; Menon, 2017; Yaraghi et al., 2018). However, health policy in the UK (especially England) similarly positions online feedback (and digital technologies more generally) as both a key facilitator of patient choice and a tool for care improvement through harnessing the patient voice (Department of Health, 2012; Department of Health and Social Care, 2016, 2015).

The blurring of 'choice' and 'voice' in this manner is not limited to online feedback (Adams, 2010). It is characteristic of a wider healthcare landscape where discourses around the democratisation of healthcare and patient empowerment overlap with and mutually reinforce an emphasis on health consumerism and patient choice (Greener, 2008). Thus, the subject (usually but not exclusively the patient) addressed in public health discourse emerges simultaneously as 'consumer' and 'citizen', despite the different logics and styles represented by these archetypes (Mol, 2008).

Associating online feedback straightforwardly with the articulation of an emancipatory patient 'voice' is problematic for a number of reasons. The dramatic growth of people sharing health experiences (including feedback) online can play a role in patient empowerment. But, digital media is not a neutral conduit. It influences the forms health activism takes,

1 contributing to an increased alignment with mainstream biomedicine and commercial  
2 enterprises (Petersen et al., 2019). Furthermore, concerns have been raised about the  
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4 commodification of health experiences, the lack of transparency around surveillance, privacy  
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6 and data ownership, and the potentially coercive and disciplinary effects of digital health  
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8 technologies based on individualised notions of self-care (Lupton, 2012, Lupton, 2014,  
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10 Millington, 2014, Schüll, 2016, Petrakaki et al., 2021).  
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17 Framing online feedback as primarily a facilitator of patient ‘choice’ is similarly problematic.  
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19 While ‘choice’ is widely endorsed as a value in healthcare, people’s ability to enact  
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21 healthcare choices is constrained and context dependent (Coulter, 2010; Powell and Boden,  
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23 2012; Fotaki, 2014). Type of healthcare service, the state of one’s health, socio-economic  
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25 status, education level, the attitude of medical professionals, geographic location and  
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27 practical considerations such as transportation and family responsibilities all influence one’s  
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29 ability to choose [healthcare services and professionals](#) (Damiani et al., 2005; Dent, 2006;  
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31 Fotaki, 2013; Greener, 2003). A number of scholars have furthermore questioned the validity  
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33 of foregrounding choice at the expense of other values in healthcare, such as ‘trust’ (Fotaki,  
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35 2014) and ‘care’ (Mol, 2008) – a critique we build on in relation to online feedback  
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37 specifically.  
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46 In this paper we move beyond an emphasis on ‘choice’ and ‘voice’ in the context of online  
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48 feedback, proposing ‘care’ and ‘conversation’ as alternative framings. Our approach is  
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50 informed by STS scholarship that has interrogated the relationship between care and  
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52 technology in contemporary healthcare (Mol, 2008, Mol et al., 2010, Roberts et al., 2012,  
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54 Pols, 2015). This work foregrounds care as a set of sensibilities and a mode of engagement  
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56 with phenomena rather than an a priori theoretical framework (Mol et al., 2010). It  
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1 approaches its subject(s) as intrinsically relational, attending to the embodied experiences,  
2 emotions, tensions and moral commitments within care practices. In a departure from a more  
3 traditional feminist ethics of care, it treats technology as part of, rather than opposed to, care  
4 relations (Mol et al., 2010, Pols, 2015). A key contribution has been to draw attention to the  
5 different, often overlooked or invisible, forms of labour implicated in digitally mediated  
6 healthcare (Oudshoorn, 2011, Roberts et al., 2012). This includes research which proposes  
7 the *moderation* of online feedback be thought of as care work (Ziewitz, 2017, Petrakaki et al.,  
8 2021). We bring the aforementioned sensibilities and insights to bear on practices of  
9 *providing* online feedback, putting our empirical findings in dialogue with social scientific  
10 literature on technologically mediated care practices and online feedback specifically.  
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### 28 3. THE ONLINE HEALTHCARE FEEDBACK LANDSCAPE IN 29 THE UK 30

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32 ‘Online patient feedback’ is used as a catchall term to describe a variety of practices and  
33 technologies, each with its own associated norms and expectations (Dudhwala et al., 2017).  
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35 In the UK, patient and other relevant service users’ experiences are collected and ideally used  
36 to improve care through numerous mechanisms: from surveys and questionnaires to the  
37 collection of ‘real time’ feedback in hospital and online platforms that allow unsolicited  
38 feedback (Marsh et al., 2019). Furthermore, the four (English, Scottish, North Irish and  
39 Welsh) devolved National Health Services conceptualise and manage feedback differently,  
40 with considerable regional variability.  
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52 Healthcare services users can provide online feedback through systems and mechanisms fully  
53 or partially managed by the NHS – such as the friends and family test (FFT)  
54 (<https://www.england.nhs.uk/fft/>) and NHS Choices (<https://www.nhs.uk>) in England. **The**  
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1 latter was rebranded after we had completed the research and is now simply called the NHS  
2 website. They can also use third party dedicated feedback platforms, such as Care Opinion  
3 ([www.careopinion.org.uk](http://www.careopinion.org.uk)) – the feedback platform of choice for the Scottish NHS (Scottish  
4 Government, 2013) – and iWantGreatCare (<https://www.iwgc.org>). NHS Choices  
5 (<https://www.nhs.uk>) is the most commonly used online platform for *writing* feedback in the  
6 UK, followed by Care Opinion (Van Velthoven et al., 2018).  
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17 In addition to ‘feeding back’ experiences through dedicated feedback systems, patients and  
18 their family members comment about their experiences on social media (e.g. health forums,  
19 Facebook, blogs, Twitter, and YouTube) and post ratings and reviews on commercial  
20 platforms (e.g. Google Reviews and Yelp). Facebook is the most commonly used social  
21 media outlet for writing feedback in the UK, followed by Google reviews (Van Velthoven et  
22 al., 2018). While this form of feedback may not always be directed *at* a healthcare provider, it  
23 is nonetheless *about them* and we thus include it here as a form of feedback.  
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36 We adopt an inclusive approach to online feedback, using the term loosely to describe  
37 publicly available comments, ratings, reviews and feedback about healthcare service  
38 experiences provided through one or more digital technology or platform. This includes both  
39 solicited (e.g. collected through the FFT) and unsolicited (e.g. posted on social media)  
40 feedback. Rather than predetermining what constituted online feedback, we asked  
41 interviewees to tell us about their experiences using and providing online feedback, ratings  
42 and reviews. We took this broad approach intentionally: first, to develop a nuanced,  
43 empirically grounded understanding of online feedback from the perspective of those  
44 providing it in the UK; second, to situate feedback practices within the wider ‘digital patient  
45 experience economy’ within which they are embedded and co-constitute (Lupton, 2014).  
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1 The people we interviewed provided online feedback in relation to their own or (sometimes  
2 multiple different) family members' healthcare experiences. Because of this, when presenting  
3 our findings, we refer to 'service user' (rather than 'patient' or 'carer') feedback. We  
4 recognise that the term 'user' (like 'patient', 'carer', 'customer' and 'citizen') carries  
5 particular associations and assumptions (Petракaki et al., 2021). When referring to or quoting  
6 directly from an interview, the capacity in which the interviewee was providing the relevant  
7 item of feedback is made clear (e.g., as a patient or a parent, etc.)  
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## 21 4. METHODS

22 The research presented here formed part of the XXXX project funded by XXXX (XXXX).  
23 The paper is based on 37 semi-structured qualitative interviews with people who used online  
24 platforms to read and/or write feedback about healthcare experiences. We recruited  
25 interviewees in a number of ways. Information about the study was posted on the project  
26 website and social media. We drew on the professional network of project members  
27 (including the study's Patients, Carers and Public Reference Group) and colleagues to  
28 advertise the study as widely as possible. Care Opinion circulated the study to users who had  
29 agreed to be contacted for research purposes. Through Google searches, XX identified  
30 bloggers and other individuals who had commented about their healthcare experiences online.  
31 She approached those with publicly available contact details to ask if they would like to  
32 participate in the study.  
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51 People who expressed interest in the research were sent an information sheet. Those who  
52 agreed to take part were interviewed in their own home, or elsewhere, if they preferred.  
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54 Written consent was sought on the day of the interview; participants were later sent a  
55 verbatim transcript of their interview to review before final consent and copyright was agreed  
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1 for publication of extracts from the interviews to be used online (e.g. for teaching, trigger  
2 films and a toolkit). Data were stored according to the requirements of the Data Protection  
3 Act 1998 and the University of XXX governance requirements. Ethical permission was given  
4 by the [ETHICS REFERENCE].  
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10 We aimed for a maximum variation sample (Coyne, 1997) that included different ages,  
11 genders and ethnicity, as well as people who had used a variety of online platforms and had  
12 commented on, or read about, different healthcare services (including primary, emergency,  
13 maternity, chronic, and specialist services). A topic guide was used to explore interviewees'  
14 general use of digital technologies, and their motivations and experiences of engaging with  
15 online healthcare-related feedback. The protocol was reviewed by the project's Patients,  
16 Carers and Public Reference Group and adjusted based on their feedback. It was used as a  
17 guide in the interviews, but participants were encouraged to speak freely about their  
18 experiences, including in relation to topics not explicitly included in the protocol.  
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33 An inductive approach was taken with two researchers (XX and XX) reading, discussing and  
34 coding the interviews throughout the data collection process. Interviewing was stopped when  
35 we ceased to identify new analytic codes and concluded the data were 'saturated'. See  
36 Table 1 for participants' basic demographic information (age, gender, ethnicity, health  
37 condition, and services used).  
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| <b>Gender</b> |             |               |
|---------------|-------------|---------------|
|               | <b>Male</b> | <b>Female</b> |
| 20-35         | 0           | 7             |
| 36-50         | 2           | 9             |
| 51-65         | 4           | 8             |
| 66+           | 6           | 1             |
| <b>Total</b>  | <b>12</b>   | <b>25</b>     |

| <b>Ethnicity</b> |                          |              |
|------------------|--------------------------|--------------|
|                  | <b>White<br/>British</b> | <b>Other</b> |
| 20-35            | 7                        | 0            |
| 36-50            | 9                        | 2            |
| 51-65            | 10                       | 2            |
| 66+              | 4                        | 3            |
| <b>Total</b>     | <b>30</b>                | <b>7</b>     |

**Health conditions and services used** (note that many of the interviewees had commented on or read about multiple conditions and services for themselves and/or family members. The list provided below is based on the *main* condition and/or service they focused on in the interview, which does not mean they did not mention other conditions or services.)

|  |           |
|--|-----------|
| Multiple complex conditions                              | 10        |
| Mental health  | 6         |
| Cancer   | 4         |
| No specific condition identified                         | 3         |
| Diabetes   | 3         |
| Care of a family member (parent or spouse, not children) | 3         |
| Childbirth (no specific condition)                       | 2         |
| Chronic pain   | 1         |
| Early onset dementia                                     | 1         |
| Heart condition  | 1         |
| Multiple Sclerosis                                       | 1         |
| Osteoarthritis and hip replacement                       | 1         |
| Spinal problems  | 1         |
| <b>Total</b>   | <b>37</b> |

Table 1: Basic participant information (age, gender, ethnicity, health condition, services).

Interviewees had used numerous, in some cases multiple, different feedback platforms. The most commonly used formal feedback platforms were Care Opinion (n=11) and NHS Choices (n=6). Interviewees had also provided feedback through Healthwatch (n=1), the NHS Friends and Family test (n=1), and various NHS websites (n=8). With regards to social media, interviewees had read and written feedback on Twitter (n=21), blogs (n=9), Facebook (n=10), and forums (n=9). The high number of people using Twitter and blogs is most likely because we advertised the study through Twitter and also because we were specifically looking for active feedback providers, a number of whom blogged about their healthcare experiences.

Transcripts were coded thematically using NVivo 10 software. We conducted an initial high-level analysis where we coded the data according to *motivations for*, *experiences of*, and *perceived effects of* reading and writing online feedback. We also coded for each platform mentioned (e.g. NHS platforms, Twitter, blogs, Facebook, Care Opinion etc.) and emergent themes such as anonymity, the public nature of feedback, and relationships with healthcare professionals. During the coding process we were struck with how interviewees articulated the relationship between their feedback practices and care improvement. In particular, how they consistently framed their online feedback as aimed at improving care for other patients and healthcare professionals.

To explore this in more depth, we did a second round of coding focused on unpacking the relationship between feedback and care improvement as described by interviewees. This resulted in themes focused on: i) online feedback and relationships with the NHS and healthcare professionals; ii) online feedback to improve care for other patients; iii) online feedback to support services, staff and the NHS; iv) conversational metaphors and care



1 improvement. Although we were familiar with STS work on care prior to the study, we had  
2 not intended to draw on it in advance of our analysis. The salience of care and conversation  
3 as lenses for thinking through online feedback emerged during the coding process. We then  
4 drew on work on the ethics of care to inform and make sense of emergent findings.  
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## 10 5. CARING FOR CARE: ONLINE FEEDBACK AS PUBLIC 11 CONVERSATION 12 13

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15 *[...] there's lots of reasons why I do it [provide online feedback]. It's not just one. [...] in*  
16 *the situation that I described at the start, that was first and foremost to try and get a*  
17 *bloody answer out of them [healthcare service provider] about what was going to happen*  
18 *next but, underlying all of this, was sharing it with other people, letting other people*  
19 *know that they're not alone and, hopefully, leading to change. But there's been other*  
20 *times where my post has been purely to highlight good practice or to instigate change in*  
21 *some way. [INQ36; female; late thirties; mental health; active feedback provider via blog,*  
22 *Care Opinion, and Twitter; NHS Scotland]*  
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37 Interviewees' provided feedback about their own or a family member's healthcare experience  
38 for a variety of reasons: to bring about changes to their care; to resolve an on-going issue; to  
39 raise concerns about care quality; to suggest improvements; to express alarm, frustration or  
40 even anger about the care received. They also used online feedback to highlight good practice  
41 and to thank, praise and acknowledge healthcare services and staff. Not only do people have  
42 many reasons for providing online feedback, they have multiple audiences in mind, from  
43 healthcare practitioners, to other patients, to regulatory authorities.  
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56 Regardless of the platform(s) used or the healthcare experience in question, interviewees  
57 invariably orientated their feedback toward *improving* and, in some cases, *transforming* care.  
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1 We unpack how interviewees spoke about the relationship between online feedback and care  
2 improvement. First, we describe interviewees' relationships with the NHS as an essential  
3 context that shaped their understandings of how online feedback could improve healthcare.  
4  
5 Second, we look at how healthcare professionals and services, and, third, other patients and  
6  
7 their family members, were positioned as key beneficiaries of online feedback. Fourth, we  
8  
9 explore the prevalence of conversational metaphors in interviewees' discussions on the  
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11 potential of online feedback to improve care.  
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### 19 5.1 'The NHS fails, we fail': contextualising online feedback in relation to 'our' NHS 20 21

22 Descriptions of how online feedback could improve care were premised on embodied, highly  
23  
24 emotive, at times ambivalent, relationships with the NHS. Interviewees recognised there was  
25  
26 not one NHS. They spoke of national and regional differences as well as differences between  
27  
28 services (e.g. mental health in contrast to primary care). They were aware of considerable  
29  
30 variability in how hospitals and other services, such as GP practices, engaged with online  
31  
32 feedback. 'The NHS' was nonetheless referenced as a single entity that needed to be  
33  
34 protected and supported. Interviewees said they 'loved' the NHS and were 'passionate' about  
35  
36 it. Some worked in the NHS (or had done so in the past) or had family members who did.  
37  
38 Criticisms and complaints, even suggestions for improvement, were juxtaposed with  
39  
40 expressions of gratitude:  
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49 *I am really, you know, very grateful that I've had life changing surgery through the*  
50  
51 *NHS, which I think is a wonderful thing. So I'm not a moaner or a complainer at all,*  
52  
53 *but I do think it's really important that we make this change to see patients as*  
54  
55 *partners in their own care and in their own recovery and having some shared*  
56  
57 *decision making. [INQ08; female; early fifties; osteoarthritis and hip replacement;*  
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1 writes about her experiences on a blog and uses NHS Choices and other websites to  
2 read others' reviews; NHS England]  
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7 The quotation above illustrates a recurring tension. Interviewees wanted their experiences to  
8 be used to improve services, but did not want to be perceived as 'moaners' or 'NHS bashers'.  
9  
10 Many used the first person plural pronoun 'we' and possessive pronouns – such as 'our' NHS  
11  
12 – to position themselves as *part of* the NHS. First person plural pronouns also indicated a  
13  
14 sense of identification and communality with other patients and fellow service users, as well  
15  
16 as a more nebulous British public dependent on the NHS:  
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24 *The NHS fails, we fail, we need the NHS to not only survive but to thrive and keep*  
25 *going and any feedback, certainly I'm giving and I know a lot of people in my position*  
26 *are, it's constructive, not because we're being critical but because need this to work.*  
27  
28 [INQ16; female, mid-thirties; multiple health conditions; active feedback provider  
29  
30 over various media blog, Twitter, Facebook, Care Opinion, different NHS websites;  
31  
32 NHS England]  
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40 Sometimes this dependency was articulated in abstract terms. But many interviewees,  
41  
42 especially those with chronic, complex or rare conditions, spoke of feeling literally dependent  
43  
44 on specific healthcare professionals. This put them in a vulnerable position. They feared  
45  
46 critical feedback would have a detrimental effect on their care, that they would be dismissed  
47  
48 as a 'serial complainer', or labelled a 'bad service user'. In such cases, the promise of  
49  
50 anonymity was a major reason interviewees turned to online feedback platforms (Speed et al.,  
51  
52 2016, Locock et al., 2020).  
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1 When online feedback is framed in terms of ‘choice’ or ‘voice’, dependency and vulnerability  
2 are ignored or seen as problems to be resolved. The patient as consumer makes rational  
3 choices unencumbered by emotions, while the patient as citizen gives voice to their  
4 experiences without fear of reprisals (Mol, 2008). In contrast, the ethics of care recognises  
5 dependency and vulnerability (on both sides) as inherent to care relations (De La Bellacasa,  
6 2011, Martin et al., 2015). From this perspective, the anonymity of online feedback is not a  
7 challenge to be overcome in order to include feedback in healthcare improvement. Rather, it  
8 is one of the things that allows people to give feedback in the first place.  
9

10 Interviewees provided feedback because they cared about the NHS as a national resource,  
11 which, *as citizens*, they felt a sense of responsibility for. At the same time, many interviewees  
12 or their family members were receiving care from specific services and professionals. Thus,  
13 *as patients*, they had to navigate the power inequalities, vulnerabilities and dependencies  
14 implicit in care relations (Martin et al., 2015). These two dimensions – *caring for* the NHS as  
15 a symbolic entity invested with emotional and ethical weight, whilst being dependent on *care*  
16 *from* NHS services and healthcare professionals – provides essential background for  
17 contextualising the practices of people providing online feedback about public healthcare  
18 services in the UK, and potentially elsewhere.  
19

## 20 5.2 ‘A public thank you’: caring for healthcare professionals and services through 21 online feedback 22

23 Feedback was seen as an important mechanism whereby patients could support, educate and  
24 inform healthcare professionals. Even when interviewees had negative experiences, they said  
25 they did not share them to be punitive, but rather, to improve professional practice. People  
26 often take considerable care when crafting online feedback (Ziewitz, 2017, Petrakaki and  
27 Kornelakis, 2021). This was certainly the case in our study where interviewees spoke of  
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1 thinking carefully about what they wrote, trying to be ‘constructive’, balancing the bad with  
2 the good, and avoiding ‘naming and shaming’ staff. Rather than being done quickly or  
3  
4 flippantly, the provision of online feedback involved considerable practical and emotional  
5  
6 labour. Active feedback providers had usually become so over time, galvanised by a sense of  
7  
8 frustration alongside a desire to improve healthcare services, as well as modes of  
9  
10 communication with them. Thus, even when critical, angry or impassioned, interviewees’  
11  
12 feedback practices were shaped by a sense of care for the NHS, or at least certain aspects of  
13  
14  
15  
16  
17 it.

18  
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21 This sense of care was particularly evident in discussions on positive feedback, which makes  
22  
23 up a large percentage of online feedback (Boylan et al., 2019). Often given alongside other  
24  
25 expressions of thanks – such as cards or chocolates – digitally recorded positive feedback  
26  
27 performed multiple functions. Interviewees wanted to ‘boost the morale’ of healthcare  
28  
29 professionals; make them feel valued and appreciated; highlight good practice; enhance  
30  
31 professional development; and support staff in gaining resources and recognition. The *public*  
32  
33 nature of online feedback was seen as having a crucial role to play in achieving these goals:  
34  
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41 *I kind of did the old-fashioned thing of sending off thankyou cards [...]but I think it’s*  
42 *also important that you take the time to speak up, when things go well and say thank*  
43 *you, and so that’s what I used Patient Opinion [Care Opinion’s name at the time] for,*  
44 *a public thank you. [INQ23; female; mid-thirties, no specific health problems*  
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1 Publicly available online feedback was perceived as reaching a wide range of audiences, be  
2 more likely to gain attention, be taken seriously and galvanise action. Online feedback was  
3  
4 also seen as something healthcare professionals could, at least potentially, leverage as  
5  
6  
7 ‘evidence’ when needed – e.g. in negotiations with external parties or regulatory bodies, such  
8  
9 as the Care Quality Commission (CQC). Interviewees frequently distinguished between  
10  
11 frontline clinical staff, whom they thought were trying their best, and those they felt were  
12  
13 undermining good care (e.g. cost-cutting bureaucrats, managers using the NHS to further a  
14  
15 political agenda, etc.). For example, in addition to providing feedback as a ‘public thank you’  
16  
17 to maternity services, the interviewee quoted above submitted online feedback both to praise  
18  
19 a baby weighing service and to register concern about its decommissioning. She hoped the  
20  
21 feedback could be used by relevant healthcare professionals to help protect the service.  
22  
23  
24 Online feedback was, therefore, both an expression of gratitude for care received and an act  
25  
26 of care for a service under threat. A similar pattern was found across interviews. For  
27  
28  
29  
30  
31 example:

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36 *I want those good experiences to be acknowledged [...] for that positive experience to*  
37  
38 *be a tool for them to use, I suppose, in terms of funding or, I don't know. I'm giving*  
39  
40 *them that information so they can use it however they want to really. [INQ22, female;*  
41  
42 *mid-thirties, mental health services, mid-thirties, blog, Twitter, NHS Choice and FFT;*  
43  
44 *NHS England]*

### 51 5.3 ‘We couldn’t walk away’: online feedback as care for other patients and their 52 families 53

54  
55 A strong sense of identification and communality with other patients was clear across the  
56  
57 interviews. While interviewees sometimes hoped their feedback would improve their own  
58  
59 care, it was more commonly aimed at improving care for other patients, or both  
60  
61

1 simultaneously. This reflects a wider phenomenon of ‘digital health citizens’ using online  
2 platforms to enact care for others (Pettrakaki et al., 2021), as vividly illustrated by a  
3  
4 participant whose concern about her parents’ care extended to the care of other patients:  
5  
6

7  
8  
9 *That was the trigger that, you know, when this lovely lady that we’d got to know and love*  
10 *as well was collapsed and had crawled into the corridor because nobody was answering*  
11 *her buzzer and it took my brothers nearly five minutes to find a nurse [...] I suppose for*  
12 *our own sanity, we wanted to feel that, well, we felt that we couldn’t walk away. We felt*  
13 *that we could not walk away knowing what we knew. And letting other people go through*  
14 *that. [INQ35; female; early-fifties; mother’s and father’s care (separate cases); feedback*  
15 *provided through Care Opinion and Twitter; NHS Scotland]*  
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27 Here, the interviewee used a combination of formal complaints, Care Opinion and Twitter to  
28 advocate on behalf of elderly patients she felt did not have a voice. In her words, providing  
29 feedback was *‘not about receiving an apology, this was about change. Real and lasting*  
30 *change’*. Although it took over three years, the campaign received political recognition and  
31 was eventually successful in galvanising reforms to elderly care services. The interviewee  
32 contrasted her experiences of providing online feedback with other, less visible, forms of  
33 feedback (including a formal complaint), which she felt had been dismissed or ignored. As  
34 elsewhere, the public nature of online feedback was foregrounded as important for bringing  
35 about change. The above is a particularly dramatic example, but the desire for feedback to be  
36 used to make tangible improvements to care services for other patients and their families was  
37 a prevalent theme throughout the interviews.  
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54 However, feedback was also provided with the aim of improving care experiences in ways  
55 that did not necessarily require actual changes to be made. For example, some interviewees  
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1 shared their healthcare experiences to help prepare others, to reassure other patients, make  
2 them feel less alone, or give them the confidence to deal with their situation:  
3  
4  
5  
6

7 *[...]I wanted to give other patients, who might be feeling equally vulnerable and*  
8 *uncomfortable asserting themselves, some confidence. To be able to say, ‘It’s okay,*  
9 *you know, if you’re not sure, it’s okay to ask questions and to request another point of*  
10 *view and, eventually, you know, you would hope that you would find somebody and*  
11 *feel comfortable, comfortable and confident in’.* [INQ08; female; early fifties;  
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osteoarthritis and hip replacement; writes about her experiences on a blog and uses  
NHS Choices and other websites to read others’ reviews; NHS England]

While interviewees said online feedback had *the potential* to inform their own and other patients’ choices, enabling choice per se was not a major reason for providing feedback. A number of interviewees explicitly rejected the logic of choice in the context of public healthcare, arguing that, unlike purchasing a product or going on holiday, healthcare was too complex and personal to equate with the consumer-orientated decision-making found in other sectors. Others said that, *in theory*, online feedback had the potential to inform patient choice, but that it was a struggle to actualise choice in the context of the NHS, with one interviewee describing NHS Choices as an ‘oxymoron’. Thus, online feedback was oriented toward improving services or helping other patients and their families be prepared for them, rather than toward assisting others in making decisions about what services to use.

#### 5.4 ‘I can’t get the NHS in for a cup of coffee and say, “Now look here NHS”’: online feedback as public conversation

Interviewees regularly framed their provision of feedback in terms of a metaphorical ‘conversation’ sought with the healthcare provider, namely ‘the NHS’. They used phrases



1 like ‘talking to’, ‘being listened to’ and ‘feeling heard by’, even while being quite clear that  
2 they were communicating with an impersonal entity (real and symbolic, singular and  
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4 multiple, at the same time):  
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8 *And so the reason that I blogged about the NHS, is because I felt that the NHS was*  
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10 *not listening, that there was no way for me to talk to the NHS. I can’t get the NHS in*  
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12 *for a cup of coffee and say, “Now look here NHS.” [INQ02; female; mid-forties*  
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14 *chronic pain condition; has provided feedback through blog, Facebook group, Twitter,*  
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16 *and NHS complaints service; NHS England]*  
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22 The metaphorical frame of ‘conversation’ (expressed in diverse ways), which pervaded  
23 interviewees’ reflections on their motivations for providing feedback adds an overlooked  
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25 dimension to the more common emphasis on feedback as articulating the patient ‘voice’.  
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27 Interviewees certainly wanted to give ‘voice’ to their experiences, and felt relief when they  
28  
29 were able to ‘get something off their chest’, but this frame was used precisely if and when the  
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31 preferred frame of ‘conversation’ seemed to fail:  
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40 *Sometimes it’s been at moments of complete desperation and I haven’t got any other*  
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42 *platform to turn to in the sense of we’re not getting anywhere with the NHS, the*  
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44 *funding, we’re just constantly having to fight for basic treatment that has been denied*  
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46 *for no reason at all. And I’ve found that it’s my way of voicing and feel like I’m being*  
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48 *heard, when I’m not being heard when I sit down and speak to someone in person.*  
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51 [INQ04; female; early twenties; Post Traumatic Stress Disorder (PTSD) following  
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53 abuse; feedback provided through blog that was featured on other media; NHS  
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However, a feedback platform was evaluated especially positively if users received a response that addressed their comments and if action(s) was taken as a result:

*I think getting a response on some level is always important. It's always nice to know you've been heard. I think it's nicer to know you've been heard by people, who have the position or knowledge to act on what you said. [INQ16; female; mid-thirties; multiple long term conditions; very active sharing experiences via blog, Twitter, Care Opinion, NHS websites, Facebook; NHS England]*

People posting online feedback do not want generic public relations style responses (Baines et al., 2018) – what one interviewee called the ‘Teflon technique’. They seek a meaningful exchange with relevant people. And yet, research conducted on Care Opinion found that only 6.5% of the 475 responses analysed were categorised as ‘a transparent conversational response’ (Ramsey et al., 2019). Thus, with notable exceptions, feedback as ‘conversation’ was something interviewees aspired to rather than actually achieved.

By being able to view others’ feedback and relevant responses on sites such as NHS Choices and Care Opinion, interviewees were aware of variations in how different providers within the NHS engaged with online feedback. They evaluated not just the online feedback platform itself, but the relevant healthcare provider as actual recipient as well. Seeing a Trust or GP practice actively engaging with online feedback had a positive influence on how interviewees perceived that provider:

*I feel quite positive about it [Care Opinion] because I feel it does feed into improving services and I like my trust because it is obviously engaging with Patient Opinion.*

1 [INQ17; female; mid-thirties; mental health; active feedback provider using Care  
2 Opinion, forums, Twitter; NHS England]  
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7 Conversely, when a care provider was unresponsive, either directly to the interviewee or  
8  
9 more generally, interviewees were disincentivised from providing feedback in the future, or  
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11 looked for alternative feedback routes:  
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17 *I've posted one or two on NHS Choices but my Trust is particularly bad at ignoring*  
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19 *them, so it seems pretty pointless doing that.* [INQ20; female; mid-sixties; mental  
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21 health and chronic back pain; active feedback provider, has used Twitter, blog, NHS  
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23 Choices, other NHS websites; NHS England]  
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29 Inconsistencies and discrepancies between providers' engagement with online feedback was  
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31 deemed especially problematic in the context of the NHS, given the assumption it was meant  
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33 to be equal, consistent and available to all, including in how feedback was managed. The  
34  
35 relevance of online feedback for care improvement therefore goes beyond tangible changes  
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37 made to care practices. The relationship sought through feedback communications is not  
38  
39 simply the enhancement of existing care relations within the healthcare system. Rather, as  
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41 feedback-related communication is itself understood as a vital form of care, it shapes care  
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43 relations in new ways. Interviewees' framing of feedback as, ideally, resembling a  
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45 'conversation' extended to the form the gathering of feedback took. Free text, narrative  
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47 feedback were preferred to checkboxes, surveys and patient satisfaction style ratings. This  
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49 was seen as enabling interviewees to 'steer' the 'conversation' and thus redress some of the  
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51 power imbalances in relationships between healthcare service providers and users.  
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## 5. CONCLUSIONS

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3 Although grounded in their own experiences and as such necessarily personal, the people we  
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5 interviewed provided online feedback in the hope it would improve care for other patients,  
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7 healthcare providers and the NHS more generally. However, the association between  
8  
9 feedback and care improvement took two analytically different, if intertwined, forms. First,  
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11 people provided online feedback in the hope it would inform healthcare services and result in  
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13 tangible changes to them. Here, feedback served as a *medium for care improvement* (i.e. a  
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15 form of advice, suggestion or recommendation directed at the service provider and aimed at  
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17 changing care services for the better). For such feedback to be deemed effective, it needed to  
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19 be picked-up and actioned by relevant healthcare professionals. Second, regardless of any  
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21 actual changes made to services, providing online feedback was experienced by interviewees  
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23 *as participation in care itself* – for example, by helping other patients and their families  
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25 prepare, by making healthcare practitioners feel appreciated, by contributing to a wider  
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27 transformations in the power dynamics between patients and healthcare service providers.  
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38 Building on an understanding of ‘good communication’ as both a crucial precondition for  
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40 good care and ‘care in and of itself’ (Mol, 2008, p.76), online feedback can be understood as  
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42 both contributing to care and as care in its own right. The ethics of care foregrounds ‘the  
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44 compelling moral salience of attending to and meeting the needs of the particular others for  
45  
46 whom we take responsibility’ (Held, 2006, p.10). Interviewees’ feedback practices were  
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48 shaped by *both* their embodied experiences of care (good and bad) *and* a strong moral  
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50 commitment to, indeed a sense of responsibility toward, other patients and service users,  
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52 healthcare professionals and services, as well as ‘the NHS’ as a highly symbolic national  
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54 resource. They were not just providing feedback on *any* healthcare service, they were  
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56 commenting on *their* healthcare services. Thus, in addition to online feedback practices being  
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1 oriented toward improving care in the two ways mentioned above, these practices should be  
2 understood as acts of care orientated toward care itself– what we refer to as *caring for care*.  
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7 Conceptualising online feedback as *caring for care*, invokes an understanding of care that is  
8 characterised as much by frustration, concern and vulnerability as by love, affection and  
9 nurture (Martin et al., 2015, p. 630). The dual weight interviewees placed on the anonymous  
10 and public nature of online feedback highlights how the personal (and private) and the  
11 political (and public) are closely coupled in online healthcare-related feedback – a point long  
12 argued in feminist care ethics more generally. People providing online feedback in the  
13 context of public healthcare services do so *both as patients* (or family members of patients)  
14 *and as public healthcare citizens*. Following Petrakaki and colleagues (Petrakaki et al., 2021),  
15 we suggest online feedback practices be understood as *productive* of particular forms of  
16 citizenship rather than representative of them. This productive dimension was particularly  
17 evident with prolific feedback providers, whose practices co-evolved overtime alongside  
18 other roles and responsibilities.  
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39 The literature on care has long recognised the mutuality – broadly understood as reciprocity,  
40 mutual influence, interdependency and a sense of common purpose (Brown, 2016) – of  
41 caring relations. However, analytical weight has usually been placed on interpersonal caring  
42 relations or on the practices of those more traditionally thought of as caregivers. We have  
43 drawn attention to how patients and other service users (typically seen as care recipients) use  
44 online feedback to enact care for healthcare professionals and services (typically seen as care  
45 providers). This prompts further questions about different ways patients and the public  
46 perform care for public services (for example, through campaigns, volunteering, bequests and  
47 donations, and so on), a topic that has to date received relatively little sociological attention.  
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1 It is widely acknowledged that digital technologies are changing how care is delivered,  
2 contributing to the emergence of new forms of distal care work (Pols, 2012, Roberts et al.,  
3 2012; Oudshoorn, 2011). A distinctive contribution of the paper is to include writing –  
4 alongside moderating (Ziewitz, 2017, Petrakaki and Kornelakis, 2021) – online feedback as a  
5 form of care work. This is based on the amount of practical and emotional labour that goes  
6 into people’s online feedback practices, but also how these practices were motivated by a  
7 sense of care, commitment and responsibility toward other patients, healthcare professionals  
8 and a ‘national’ healthcare system. This contrasts with an understanding of feedback as done  
9 quickly or even flippantly.  
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24 Acknowledging the labour of providing online feedback highlights the importance of  
25 receiving an appropriate response. While interviewees did value the opportunity to give  
26 ‘voice’ to their experiences, this was not in itself sufficient. Ideally, they wanted feedback to  
27 be a ‘conversation’. Open, publicly available ‘conversation’ was, in fact, a key mechanism  
28 through which they sought to enact care for care, though this, in practice, for the most part,  
29 remained an ideal rather than an actuality.  
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41 One side effect of publicly available online healthcare-related feedback in the UK is that  
42 people can see the responses and assess the relative responsiveness of different healthcare  
43 services. This has consequences for perceptions of and relationships with said service  
44 providers. Given the steady growth in online feedback, this is increasingly pertinent for NHS  
45 healthcare service providers. Currently, it is rare for healthcare service provider responses to  
46 be either conversational or transparent (Baines et al., 2018; Ramsey et al., 2019), and most  
47 healthcare improvement initiatives still rely primarily on solicited survey data (Gleeson et al.,  
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2016). Nonetheless, when taken seriously, online feedback has the potential to tangibly improve care practices and relations (Munro, 2017).

Our analysis has emphasised that, as both citizens and patients, healthcare service users in the UK turn to online feedback to enact care for ‘the NHS’. While our findings are distinctive to the UK and the NHS as a national institution, we hypothesize that elements of them will apply in other contexts where citizens feel both responsible for and dependent on public healthcare systems. Similarly, it is likely that aspects of ‘caring for care’ are present in systems where patients pay more directly for their healthcare, given that here too people develop complex, emotionally charged, often long-standing, relationships with healthcare services, especially in contexts of chronic illness. However, given the importance of situating online feedback practices within *different* contexts and relationships, further in-depth qualitative studies are needed to ascertain what aspects of our findings are particularly pertinent for the wider international phenomena of online healthcare-related feedback. In particular, we would like to see research that interrogates the role different online platforms play in enabling online feedback to be understood as integral to care and, crucially on the perspective of healthcare professionals, institutions, and organisations on this.

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# Caring for Care: Online Feedback in the Context of Public Healthcare Services

## 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. Online feedback has also been critiqued for being unrepresentative, spreading inaccurate information, undermining care relations, and jeopardising professional autonomy. Through a thematic analysis of 37 qualitative interviews, this paper explores the relationship between online feedback and care improvement as articulated by healthcare service users (patients and family members) who provided feedback across different online platforms and social media in the UK.

Online feedback was framed by interviewees as, ideally, a public and, in many cases, anonymous ‘conversation’ between service users and healthcare providers. These ‘conversations’ were thought of not merely as bringing about tangible improvements to healthcare practices, but as *in themselves* constituting an improvement in care. Vital to this was the premise that providing feedback was an *enactment of care* – care for other patients, certainly, but also care for healthcare as such and even for healthcare professionals. Ultimately, feedback was understood as an enactment of care for the National Health Service (NHS), as symbolically encompassing all of the above.

Putting these findings in dialogue with STS scholarship on care, we argue that, in this context, the provision of online feedback can be understood as a *form of care* that is, simultaneously, both *directed at* healthcare (in the round, including patients, professionals, services, organisations, and, of course, health itself) and *part of* healthcare. We conceptualise this as ‘caring for care’. This conceptualisation moves beyond dominant framings of online feedback in terms of ‘choice’ and ‘voice’. It embeds online feedback within pre-existing healthcare systems, relations and moral commitments, foregrounds the mutuality of care relations, and draws attention to the affective labour of feedback practices.

**Keywords:** UK; NHS; Digital Technologies; Care; Online Feedback; Qualitative Interviews.



# 1. INTRODUCTION

Over the past decade, the number of people who go online to rate, review and provide feedback about their healthcare experiences has been slowly and steadily growing (Gao et al., 2012; Greaves and Millett, 2012; van Velthoven et al., 2018). This trend has been met with considerable concern from healthcare professionals, with fears expressed about accuracy and representativeness, as well as implications for care relations and professional (in particular medical) autonomy (McCartney, 2009; Patel et al., 2015; Samora et al., 2016; Menon, 2017; Atherton et al., 2019). At the same time, online feedback promises to enhance patient power, choice and control, encourage greater transparency and accountability, and contribute to healthcare service improvement in a cost effective manner (Greaves et al., 2012; van de Belt et al., 2015; Browne and Shaller, 2018).

Survey research indicates that 42% of UK internet users (n=1824) have read some form of healthcare-related feedback online, while only 8% have provided feedback about their own experiences (van Velthoven et al., 2018). This pattern is consistent with health-related social media use, where the number of people reading about healthcare experiences far outstrips those providing it (Mierlo, 2014). Thus, the feedback practices of a relatively small group has the potential to affect a much wider pool of patients, their family members and healthcare professionals.

A key concern expressed by healthcare professionals, especially doctors, is that online feedback is produced by an unrepresentative minority expressing extreme views and, as such, is of limited value for healthcare improvement (Atherton et al., 2019; Patel et al., 2015).

However, rather than being dominated by disgruntled service users and complaints, much online healthcare-related feedback is positive (Kadry et al., 2011; Lagu et al., 2013; Emmert

1 et al., 2014; Emmert et al., 2015; Greaves et al., 2012; Menon, 2017; Liu et al., 2018; Powell  
2 et al., 2019). This tendency has remained consistent over time, across national healthcare  
3 systems, different medical specialists and feedback platforms (Boylan et al., 2019).  
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9 Despite their central importance to the online feedback landscape, little is known about how  
10 those providing feedback in different healthcare contexts understand their own practices  
11 (Boylan et al., 2019). Drawing on 37 qualitative interviews with people who read (n= 37)  
12 and/or wrote (n=32) online feedback about their own or a family member's experiences of the  
13 National Health Service (NHS) in England (n=34) and Scotland (n=3), this paper analyses  
14 experiences of and motivations for providing online feedback. It focuses on how people who  
15 posted online feedback across different platforms in the UK understood the relationship  
16 between online feedback and care improvement.  
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31 The paper foregrounds four aspects of the relationship between online feedback and care  
32 improvement as articulated by interviewees. One, understandings of how online feedback  
33 might improve healthcare were premised on pre-existing embodied, emotive and, at times  
34 ambivalent, relationships with the NHS. Two, healthcare professionals and services were  
35 positioned as both subjects and beneficiaries of online feedback. Three, a major motivation  
36 for providing feedback was to improve care for other patients and their families, with whom  
37 interviewees felt a strong identification and communality. Fourth, interviewees wanted online  
38 feedback to, ideally, take the form of a two-way 'conversation' between service users and  
39 healthcare providers. Across all four, the public and anonymous nature of online feedback  
40 were foregrounded as crucial facilitators of care improvement.  
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In what follows, we put these findings in dialogue with Science and Technology Studies (STS) work on the ethics of care. Through our analysis we suggest online feedback be understood as a way healthcare service users (patients and their family members) *enact care* for other patients and their families, but also, significantly, for healthcare practitioners and services – what we conceptualise as ‘caring for care’. A key way interviewees hoped online feedback could facilitate this particular form of care is through publicly available (often anonymous) digitally mediated feedback ‘conversations’.

Most extant research and health policy has framed online feedback in terms of patient ‘choice’ or ‘voice’, or a conjoining of the two with capturing the patient ‘voice’ seen as a means of enhancing ‘choice’ (Adams, 2010; Powell et al., 2019). We argue that even when modelled on systems used by commercial enterprises, online healthcare feedback cannot be conceptualised as consumerist behaviour aimed at reinforcing patient choice; nor as a means of democratising the technocratic instrument of quality control through harnessing the patient’s voice. Instead, we propose ‘care’ and ‘conversation’ as alternative framings for understanding online feedback practices in the context of public healthcare systems. This dual conceptualisation foregrounds the mutuality of care relations and highlights the affective labour of feedback practices. Furthermore, it draws attention to two ways online feedback can improve care: first, through prompting tangible changes to healthcare services – online feedback *for* healthcare improvement; second, as a form of care improvement in its own right – feedback *as* healthcare improvement.

## 2. ONLINE HEALTHCARE FEEDBACK: GOING BEYOND 'CHOICE' AND 'VOICE'

Much academic literature on online healthcare-related feedback has come from the US and Germany, but there is a growing body of work in different healthcare systems, including free at point of use systems like the NHS in the UK (Boylan et al., 2019). The link between feedback and patient-consumer choice is, unsurprisingly, a common theme in studies from countries with private healthcare systems, like the US, and in relation to elective procedures such as plastic surgery (Hanauer et al., 2014; Menon, 2017; Yaraghi et al., 2018). However, health policy in the UK (especially England) similarly positions online feedback (and digital technologies more generally) as both a key facilitator of patient choice and a tool for care improvement through harnessing the patient voice (Department of Health, 2012; Department of Health and Social Care, 2016, 2015).

The blurring of 'choice' and 'voice' in this manner is not limited to online feedback (Adams, 2010). It is characteristic of a wider healthcare landscape where discourses around the democratisation of healthcare and patient empowerment overlap with and mutually reinforce an emphasis on health consumerism and patient choice (Greener, 2008). Thus, the subject (usually but not exclusively the patient) addressed in public health discourse emerges simultaneously as 'consumer' and 'citizen', despite the different logics and styles represented by these archetypes (Mol, 2008).

Associating online feedback straightforwardly with the articulation of an emancipatory patient 'voice' is problematic for a number of reasons. The dramatic growth of people sharing health experiences (including feedback) online can play a role in patient empowerment. But, digital media is not a neutral conduit. It influences the forms health activism takes,

1 contributing to an increased alignment with mainstream biomedicine and commercial  
2 enterprises (Petersen et al., 2019). Furthermore, concerns have been raised about the  
3  
4 commodification of health experiences, the lack of transparency around surveillance, privacy  
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6 and data ownership, and the potentially coercive and disciplinary effects of digital health  
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8 technologies based on individualised notions of self-care (Lupton, 2012, Lupton, 2014,  
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10 Millington, 2014, Schüll, 2016, Petrakaki et al., 2021).  
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17 Framing online feedback as primarily a facilitator of patient ‘choice’ is similarly problematic.  
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19 While ‘choice’ is widely endorsed as a value in healthcare, people’s ability to enact  
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21 healthcare choices is constrained and context dependent (Coulter, 2010; Powell and Boden,  
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23 2012; Fotaki, 2014). Type of healthcare service, the state of one’s health, socio-economic  
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25 status, education level, the attitude of medical professionals, geographic location and  
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27 practical considerations such as transportation and family responsibilities all influence one’s  
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29 ability to choose healthcare services and professionals (Damiani et al., 2005; Dent, 2006;  
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31 Fotaki, 2013; Greener, 2003). A number of scholars have furthermore questioned the validity  
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33 of foregrounding choice at the expense of other values in healthcare, such as ‘trust’ (Fotaki,  
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35 2014) and ‘care’ (Mol, 2008) – a critique we build on in relation to online feedback  
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37 specifically.  
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46 In this paper we move beyond an emphasis on ‘choice’ and ‘voice’ in the context of online  
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48 feedback, proposing ‘care’ and ‘conversation’ as alternative framings. Our approach is  
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50 informed by STS scholarship that has interrogated the relationship between care and  
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52 technology in contemporary healthcare (Mol, 2008, Mol et al., 2010, Roberts et al., 2012,  
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54 Pols, 2015). This work foregrounds care as a set of sensibilities and a mode of engagement  
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56 with phenomena rather than an a priori theoretical framework (Mol et al., 2010). It  
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1 approaches its subject(s) as intrinsically relational, attending to the embodied experiences,  
2 emotions, tensions and moral commitments within care practices. In a departure from a more  
3 traditional feminist ethics of care, it treats technology as part of, rather than opposed to, care  
4 relations (Mol et al., 2010, Pols, 2015). A key contribution has been to draw attention to the  
5 different, often overlooked or invisible, forms of labour implicated in digitally mediated  
6 healthcare (Oudshoorn, 2011, Roberts et al., 2012). This includes research which proposes  
7 the *moderation* of online feedback be thought of as care work (Ziewitz, 2017, Petrakaki et al.,  
8 2021). We bring the aforementioned sensibilities and insights to bear on practices of  
9 *providing* online feedback, putting our empirical findings in dialogue with social scientific  
10 literature on technologically mediated care practices and online feedback specifically.  
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### 28 3. THE ONLINE HEALTHCARE FEEDBACK LANDSCAPE IN 29 THE UK 30

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32 ‘Online patient feedback’ is used as a catchall term to describe a variety of practices and  
33 technologies, each with its own associated norms and expectations (Dudhwala et al., 2017).  
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35 In the UK, patient and other relevant service users’ experiences are collected and ideally used  
36 to improve care through numerous mechanisms: from surveys and questionnaires to the  
37 collection of ‘real time’ feedback in hospital and online platforms that allow unsolicited  
38 feedback (Marsh et al., 2019). Furthermore, the four (English, Scottish, North Irish and  
39 Welsh) devolved National Health Services conceptualise and manage feedback differently,  
40 with considerable regional variability.  
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52 Healthcare services users can provide online feedback through systems and mechanisms fully  
53 or partially managed by the NHS – such as the friends and family test (FFT)  
54 (<https://www.england.nhs.uk/fft/>) and NHS Choices (<https://www.nhs.uk>) in England. The  
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1 latter was rebranded after we had completed the research and is now simply called the NHS  
2 website. They can also use third party dedicated feedback platforms, such as Care Opinion  
3 ([www.careopinion.org.uk](http://www.careopinion.org.uk)) – the feedback platform of choice for the Scottish NHS (Scottish  
4 Government, 2013) – and iWantGreatCare (<https://www.iwgc.org>). NHS Choices  
5 (<https://www.nhs.uk>) is the most commonly used online platform for *writing* feedback in the  
6 UK, followed by Care Opinion (Van Velthoven et al., 2018).  
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17 In addition to ‘feeding back’ experiences through dedicated feedback systems, patients and  
18 their family members comment about their experiences on social media (e.g. health forums,  
19 Facebook, blogs, Twitter, and YouTube) and post ratings and reviews on commercial  
20 platforms (e.g. Google Reviews and Yelp). Facebook is the most commonly used social  
21 media outlet for writing feedback in the UK, followed by Google reviews (Van Velthoven et  
22 al., 2018). While this form of feedback may not always be directed *at* a healthcare provider, it  
23 is nonetheless *about them* and we thus include it here as a form of feedback.  
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36 We adopt an inclusive approach to online feedback, using the term loosely to describe  
37 publicly available comments, ratings, reviews and feedback about healthcare service  
38 experiences provided through one or more digital technology or platform. This includes both  
39 solicited (e.g. collected through the FFT) and unsolicited (e.g. posted on social media)  
40 feedback. Rather than predetermining what constituted online feedback, we asked  
41 interviewees to tell us about their experiences using and providing online feedback, ratings  
42 and reviews. We took this broad approach intentionally: first, to develop a nuanced,  
43 empirically grounded understanding of online feedback from the perspective of those  
44 providing it in the UK; second, to situate feedback practices within the wider ‘digital patient  
45 experience economy’ within which they are embedded and co-constitute (Lupton, 2014).  
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1 The people we interviewed provided online feedback in relation to their own or (sometimes  
2 multiple different) family members' healthcare experiences. Because of this, when presenting  
3 our findings, we refer to 'service user' (rather than 'patient' or 'carer') feedback. We  
4 recognise that the term 'user' (like 'patient', 'carer', 'customer' and 'citizen') carries  
5 particular associations and assumptions (Petракaki et al., 2021). When referring to or quoting  
6 directly from an interview, the capacity in which the interviewee was providing the relevant  
7 item of feedback is made clear (e.g., as a patient or a parent, etc.)  
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## 21 4. METHODS

22 The research presented here formed part of the XXXX project funded by XXXX (XXXX).  
23 The paper is based on 37 semi-structured qualitative interviews with people who used online  
24 platforms to read and/or write feedback about healthcare experiences. We recruited  
25 interviewees in a number of ways. Information about the study was posted on the project  
26 website and social media. We drew on the professional network of project members  
27 (including the study's Patients, Carers and Public Reference Group) and colleagues to  
28 advertise the study as widely as possible. Care Opinion circulated the study to users who had  
29 agreed to be contacted for research purposes. Through Google searches, XX identified  
30 bloggers and other individuals who had commented about their healthcare experiences online.  
31 She approached those with publicly available contact details to ask if they would like to  
32 participate in the study.  
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51 People who expressed interest in the research were sent an information sheet. Those who  
52 agreed to take part were interviewed in their own home, or elsewhere, if they preferred.  
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54 Written consent was sought on the day of the interview; participants were later sent a  
55 verbatim transcript of their interview to review before final consent and copyright was agreed  
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1 for publication of extracts from the interviews to be used online (e.g. for teaching, trigger  
2 films and a toolkit). Data were stored according to the requirements of the Data Protection  
3 Act 1998 and the University of XXX governance requirements. Ethical permission was given  
4 by the [ETHICS REFERENCE].  
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10 We aimed for a maximum variation sample (Coyne, 1997) that included different ages,  
11 genders and ethnicity, as well as people who had used a variety of online platforms and had  
12 commented on, or read about, different healthcare services (including primary, emergency,  
13 maternity, chronic, and specialist services). A topic guide was used to explore interviewees'  
14 general use of digital technologies, and their motivations and experiences of engaging with  
15 online healthcare-related feedback. The protocol was reviewed by the project's Patients,  
16 Carers and Public Reference Group and adjusted based on their feedback. It was used as a  
17 guide in the interviews, but participants were encouraged to speak freely about their  
18 experiences, including in relation to topics not explicitly included in the protocol.  
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33 An inductive approach was taken with two researchers (XX and XX) reading, discussing and  
34 coding the interviews throughout the data collection process. Interviewing was stopped when  
35 we ceased to identify new analytic codes and concluded the data were 'saturated'. See Table  
36 1 for participants' basic demographic information (age, gender, ethnicity, health condition,  
37 and services used).  
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| <b>Gender</b> |             |               |
|---------------|-------------|---------------|
|               | <b>Male</b> | <b>Female</b> |
| 20-35         | 0           | 7             |
| 36-50         | 2           | 9             |
| 51-65         | 4           | 8             |
| 66+           | 6           | 1             |
| <b>Total</b>  | <b>12</b>   | <b>25</b>     |

| <b>Ethnicity</b> |                          |              |
|------------------|--------------------------|--------------|
|                  | <b>White<br/>British</b> | <b>Other</b> |
| 20-35            | 7                        | 0            |
| 36-50            | 9                        | 2            |
| 51-65            | 10                       | 2            |
| 66+              | 4                        | 3            |
| <b>Total</b>     | <b>30</b>                | <b>7</b>     |

**Health conditions and services used** (note that many of the interviewees had commented on or read about multiple conditions and services for themselves and/or family members. The list provided below is based on the *main* condition and/or service they focused on in the interview, which does not mean they did not mention other conditions or services.)

|  |           |
|--|-----------|
| Multiple complex conditions                              | 10        |
| Mental health  | 6         |
| Cancer   | 4         |
| No specific condition identified                         | 3         |
| Diabetes   | 3         |
| Care of a family member (parent or spouse, not children) | 3         |
| Childbirth (no specific condition)                       | 2         |
| Chronic pain   | 1         |
| Early onset dementia                                     | 1         |
| Heart condition  | 1         |
| Multiple Sclerosis                                       | 1         |
| Osteoarthritis and hip replacement                       | 1         |
| Spinal problems  | 1         |
| <b>Total</b>   | <b>37</b> |

Table 1: Basic participant information (age, gender, ethnicity, health condition, services).

Interviewees had used numerous, in some cases multiple, different feedback platforms. The most commonly used formal feedback platforms were Care Opinion (n=11) and NHS Choices (n=6). Interviewees had also provided feedback through Healthwatch (n=1), the NHS Friends and Family test (n=1), and various NHS websites (n=8). With regards to social media, interviewees had read and written feedback on Twitter (n=21), blogs (n=9), Facebook (n=10), and forums (n=9). The high number of people using Twitter and blogs is most likely because we advertised the study through Twitter and also because we were specifically looking for active feedback providers, a number of whom blogged about their healthcare experiences.

Transcripts were coded thematically using NVivo 10 software. We conducted an initial high-level analysis where we coded the data according to *motivations for*, *experiences of*, and *perceived effects of* reading and writing online feedback. We also coded for each platform mentioned (e.g. NHS platforms, Twitter, blogs, Facebook, Care Opinion etc.) and emergent themes such as anonymity, the public nature of feedback, and relationships with healthcare professionals. During the coding process we were struck with how interviewees articulated the relationship between their feedback practices and care improvement. In particular, how they consistently framed their online feedback as aimed at improving care for other patients and healthcare professionals.

To explore this in more depth, we did a second round of coding focused on unpacking the relationship between feedback and care improvement as described by interviewees. This resulted in themes focused on: i) online feedback and relationships with the NHS and healthcare professionals; ii) online feedback to improve care for other patients; iii) online feedback to support services, staff and the NHS; iv) conversational metaphors and care

1 improvement. Although we were familiar with STS work on care prior to the study, we had  
2 not intended to draw on it in advance of our analysis. The salience of care and conversation  
3 as lenses for thinking through online feedback emerged during the coding process. We then  
4 drew on work on the ethics of care to inform and make sense of emergent findings.  
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## 10 5. CARING FOR CARE: ONLINE FEEDBACK AS PUBLIC 11 CONVERSATION 12 13

14  
15 *[...] there's lots of reasons why I do it [provide online feedback]. It's not just one. [...] in*  
16 *the situation that I described at the start, that was first and foremost to try and get a*  
17 *bloody answer out of them [healthcare service provider] about what was going to happen*  
18 *next but, underlying all of this, was sharing it with other people, letting other people*  
19 *know that they're not alone and, hopefully, leading to change. But there's been other*  
20 *times where my post has been purely to highlight good practice or to instigate change in*  
21 *some way. [INQ36; female; late thirties; mental health; active feedback provider via blog,*  
22 *Care Opinion, and Twitter; NHS Scotland]*  
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37 Interviewees' provided feedback about their own or a family member's healthcare experience  
38 for a variety of reasons: to bring about changes to their care; to resolve an on-going issue; to  
39 raise concerns about care quality; to suggest improvements; to express alarm, frustration or  
40 even anger about the care received. They also used online feedback to highlight good practice  
41 and to thank, praise and acknowledge healthcare services and staff. Not only do people have  
42 many reasons for providing online feedback, they have multiple audiences in mind, from  
43 healthcare practitioners, to other patients, to regulatory authorities.  
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56 Regardless of the platform(s) used or the healthcare experience in question, interviewees  
57 invariably orientated their feedback toward *improving* and, in some cases, *transforming* care.  
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1 We unpack how interviewees spoke about the relationship between online feedback and care  
2 improvement. First, we describe interviewees' relationships with the NHS as an essential  
3 context that shaped their understandings of how online feedback could improve healthcare.  
4  
5 Second, we look at how healthcare professionals and services, and, third, other patients and  
6  
7 their family members, were positioned as key beneficiaries of online feedback. Fourth, we  
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9 explore the prevalence of conversational metaphors in interviewees' discussions on the  
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11 potential of online feedback to improve care.  
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### 20 5.1 'The NHS fails, we fail': contextualising online feedback in relation to 'our' NHS

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22 Descriptions of how online feedback could improve care were premised on embodied, highly  
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24 emotive, at times ambivalent, relationships with the NHS. Interviewees recognised there was  
25  
26 not one NHS. They spoke of national and regional differences as well as differences between  
27  
28 services (e.g. mental health in contrast to primary care). They were aware of considerable  
29  
30 variability in how hospitals and other services, such as GP practices, engaged with online  
31  
32 feedback. 'The NHS' was nonetheless referenced as a single entity that needed to be  
33  
34 protected and supported. Interviewees said they 'loved' the NHS and were 'passionate' about  
35  
36 it. Some worked in the NHS (or had done so in the past) or had family members who did.  
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38 Criticisms and complaints, even suggestions for improvement, were juxtaposed with  
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40 expressions of gratitude:  
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49 *I am really, you know, very grateful that I've had life changing surgery through the*  
50 *NHS, which I think is a wonderful thing. So I'm not a moaner or a complainer at all,*  
51 *but I do think it's really important that we make this change to see patients as*  
52 *partners in their own care and in their own recovery and having some shared*  
53 *decision making. [INQ08; female; early fifties; osteoarthritis and hip replacement;*  
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1 writes about her experiences on a blog and uses NHS Choices and other websites to  
2 read others' reviews; NHS England]  
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7 The quotation above illustrates a recurring tension. Interviewees wanted their experiences to  
8 be used to improve services, but did not want to be perceived as 'moaners' or 'NHS bashers'.  
9  
10 Many used the first person plural pronoun 'we' and possessive pronouns – such as 'our' NHS  
11  
12 – to position themselves as *part of* the NHS. First person plural pronouns also indicated a  
13  
14 sense of identification and communality with other patients and fellow service users, as well  
15  
16 as a more nebulous British public dependent on the NHS:  
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24 *The NHS fails, we fail, we need the NHS to not only survive but to thrive and keep*  
25 *going and any feedback, certainly I'm giving and I know a lot of people in my position*  
26 *are, it's constructive, not because we're being critical but because need this to work.*  
27  
28 [INQ16; female, mid-thirties; multiple health conditions; active feedback provider  
29  
30 over various media blog, Twitter, Facebook, Care Opinion, different NHS websites;  
31  
32 NHS England]  
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40 Sometimes this dependency was articulated in abstract terms. But many interviewees,  
41  
42 especially those with chronic, complex or rare conditions, spoke of feeling literally dependent  
43  
44 on specific healthcare professionals. This put them in a vulnerable position. They feared  
45  
46 critical feedback would have a detrimental effect on their care, that they would be dismissed  
47  
48 as a 'serial complainer', or labelled a 'bad service user'. In such cases, the promise of  
49  
50 anonymity was a major reason interviewees turned to online feedback platforms (Speed et al.,  
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52 2016, Locock et al., 2020).  
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1 When online feedback is framed in terms of ‘choice’ or ‘voice’, dependency and vulnerability  
2 are ignored or seen as problems to be resolved. The patient as consumer makes rational  
3 choices unencumbered by emotions, while the patient as citizen gives voice to their  
4 experiences without fear of reprisals (Mol, 2008). In contrast, the ethics of care recognises  
5 dependency and vulnerability (on both sides) as inherent to care relations (De La Bellacasa,  
6 2011, Martin et al., 2015). From this perspective, the anonymity of online feedback is not a  
7 challenge to be overcome in order to include feedback in healthcare improvement. Rather, it  
8 is one of the things that allows people to give feedback in the first place.  
9

10 Interviewees provided feedback because they cared about the NHS as a national resource,  
11 which, *as citizens*, they felt a sense of responsibility for. At the same time, many interviewees  
12 or their family members were receiving care from specific services and professionals. Thus,  
13 *as patients*, they had to navigate the power inequalities, vulnerabilities and dependencies  
14 implicit in care relations (Martin et al., 2015). These two dimensions – *caring for* the NHS as  
15 a symbolic entity invested with emotional and ethical weight, whilst being dependent on *care*  
16 *from* NHS services and healthcare professionals – provides essential background for  
17 contextualising the practices of people providing online feedback about public healthcare  
18 services in the UK, and potentially elsewhere.  
19

## 20 5.2 ‘A public thank you’: caring for healthcare professionals and services through 21 online feedback

22 Feedback was seen as an important mechanism whereby patients could support, educate and  
23 inform healthcare professionals. Even when interviewees had negative experiences, they said  
24 they did not share them to be punitive, but rather, to improve professional practice. People  
25 often take considerable care when crafting online feedback (Ziewitz, 2017, Petrakaki and  
26 Kornelakis, 2021). This was certainly the case in our study where interviewees spoke of  
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1 thinking carefully about what they wrote, trying to be ‘constructive’, balancing the bad with  
2 the good, and avoiding ‘naming and shaming’ staff. Rather than being done quickly or  
3  
4 flippantly, the provision of online feedback involved considerable practical and emotional  
5  
6 labour. Active feedback providers had usually become so over time, galvanised by a sense of  
7  
8 frustration alongside a desire to improve healthcare services, as well as modes of  
9  
10 communication with them. Thus, even when critical, angry or impassioned, interviewees’  
11  
12 feedback practices were shaped by a sense of care for the NHS, or at least certain aspects of  
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17 it.

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21 This sense of care was particularly evident in discussions on positive feedback, which makes  
22  
23 up a large percentage of online feedback (Boylan et al., 2019). Often given alongside other  
24  
25 expressions of thanks – such as cards or chocolates – digitally recorded positive feedback  
26  
27 performed multiple functions. Interviewees wanted to ‘boost the morale’ of healthcare  
28  
29 professionals; make them feel valued and appreciated; highlight good practice; enhance  
30  
31 professional development; and support staff in gaining resources and recognition. The *public*  
32  
33 nature of online feedback was seen as having a crucial role to play in achieving these goals:  
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41 *I kind of did the old-fashioned thing of sending off thankyou cards [...]but I think it’s*  
42  
43 *also important that you take the time to speak up, when things go well and say thank*  
44  
45 *you, and so that’s what I used Patient Opinion [Care Opinion’s name at the time] for,*  
46  
47 *a public thank you. [INQ23; female; mid-thirties, no specific health problems*  
48  
49 *feedback provided about maternity services; used Care Opinion to provide feedback,*  
50  
51 *reads others’ feedback on different platforms; NHS England]*  
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1 Publicly available online feedback was perceived as reaching a wide range of audiences, be  
2 more likely to gain attention, be taken seriously and galvanise action. Online feedback was  
3  
4 also seen as something healthcare professionals could, at least potentially, leverage as  
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7 ‘evidence’ when needed – e.g. in negotiations with external parties or regulatory bodies, such  
8  
9 as the Care Quality Commission (CQC). Interviewees frequently distinguished between  
10  
11 frontline clinical staff, whom they thought were trying their best, and those they felt were  
12  
13 undermining good care (e.g. cost-cutting bureaucrats, managers using the NHS to further a  
14  
15 political agenda, etc.). For example, in addition to providing feedback as a ‘public thank you’  
16  
17 to maternity services, the interviewee quoted above submitted online feedback both to praise  
18  
19 a baby weighing service and to register concern about its decommissioning. She hoped the  
20  
21 feedback could be used by relevant healthcare professionals to help protect the service.  
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23  
24 Online feedback was, therefore, both an expression of gratitude for care received and an act  
25  
26 of care for a service under threat. A similar pattern was found across interviews. For  
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31 example:

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36 *I want those good experiences to be acknowledged [...] for that positive experience to*  
37  
38 *be a tool for them to use, I suppose, in terms of funding or, I don't know. I'm giving*  
39  
40 *them that information so they can use it however they want to really. [INQ22, female;*  
41  
42 *mid-thirties, mental health services, mid-thirties, blog, Twitter, NHS Choice and FFT;*  
43  
44 *NHS England]*

### 51 5.3 ‘We couldn’t walk away’: online feedback as care for other patients and their 52 families 53

54  
55 A strong sense of identification and communality with other patients was clear across the  
56  
57 interviews. While interviewees sometimes hoped their feedback would improve their own  
58  
59 care, it was more commonly aimed at improving care for other patients, or both  
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1 simultaneously. This reflects a wider phenomenon of ‘digital health citizens’ using online  
2 platforms to enact care for others (Pettrakaki et al., 2021), as vividly illustrated by a  
3  
4 participant whose concern about her parents’ care extended to the care of other patients:  
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9 *That was the trigger that, you know, when this lovely lady that we’d got to know and love*  
10 *as well was collapsed and had crawled into the corridor because nobody was answering*  
11 *her buzzer and it took my brothers nearly five minutes to find a nurse [...] I suppose for*  
12 *our own sanity, we wanted to feel that, well, we felt that we couldn’t walk away. We felt*  
13 *that we could not walk away knowing what we knew. And letting other people go through*  
14 *that. [INQ35; female; early-fifties; mother’s and father’s care (separate cases); feedback*  
15 *provided through Care Opinion and Twitter; NHS Scotland]*  
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27 Here, the interviewee used a combination of formal complaints, Care Opinion and Twitter to  
28 advocate on behalf of elderly patients she felt did not have a voice. In her words, providing  
29 feedback was *‘not about receiving an apology, this was about change. Real and lasting*  
30 *change’*. Although it took over three years, the campaign received political recognition and  
31 was eventually successful in galvanising reforms to elderly care services. The interviewee  
32 contrasted her experiences of providing online feedback with other, less visible, forms of  
33 feedback (including a formal complaint), which she felt had been dismissed or ignored. As  
34 elsewhere, the public nature of online feedback was foregrounded as important for bringing  
35 about change. The above is a particularly dramatic example, but the desire for feedback to be  
36 used to make tangible improvements to care services for other patients and their families was  
37 a prevalent theme throughout the interviews.  
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54 However, feedback was also provided with the aim of improving care experiences in ways  
55 that did not necessarily require actual changes to be made. For example, some interviewees  
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1 shared their healthcare experiences to help prepare others, to reassure other patients, make  
2 them feel less alone, or give them the confidence to deal with their situation:  
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7 *[...]I wanted to give other patients, who might be feeling equally vulnerable and*  
8 *uncomfortable asserting themselves, some confidence. To be able to say, ‘It’s okay,*  
9 *you know, if you’re not sure, it’s okay to ask questions and to request another point of*  
10 *view and, eventually, you know, you would hope that you would find somebody and*  
11 *feel comfortable, comfortable and confident in’.* [INQ08; female; early fifties;  
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osteoarthritis and hip replacement; writes about her experiences on a blog and uses  
NHS Choices and other websites to read others’ reviews; NHS England]

While interviewees said online feedback had *the potential* to inform their own and other patients’ choices, enabling choice per se was not a major reason for providing feedback. A number of interviewees explicitly rejected the logic of choice in the context of public healthcare, arguing that, unlike purchasing a product or going on holiday, healthcare was too complex and personal to equate with the consumer-orientated decision-making found in other sectors. Others said that, *in theory*, online feedback had the potential to inform patient choice, but that it was a struggle to actualise choice in the context of the NHS, with one interviewee describing NHS Choices as an ‘oxymoron’. Thus, online feedback was oriented toward improving services or helping other patients and their families be prepared for them, rather than toward assisting others in making decisions about what services to use.

#### 5.4 ‘I can’t get the NHS in for a cup of coffee and say, “Now look here NHS”’: online feedback as public conversation

Interviewees regularly framed their provision of feedback in terms of a metaphorical ‘conversation’ sought with the healthcare provider, namely ‘the NHS’. They used phrases

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like ‘talking to’, ‘being listened to’ and ‘feeling heard by’, even while being quite clear that they were communicating with an impersonal entity (real and symbolic, singular and multiple, at the same time):

*And so the reason that I blogged about the NHS, is because I felt that the NHS was not listening, that there was no way for me to talk to the NHS. I can't get the NHS in for a cup of coffee and say, "Now look here NHS." [INQ02; female; mid-forties chronic pain condition; has provided feedback through blog, Facebook group, Twitter, and NHS complaints service; NHS England]*

The metaphorical frame of ‘conversation’ (expressed in diverse ways), which pervaded interviewees’ reflections on their motivations for providing feedback adds an overlooked dimension to the more common emphasis on feedback as articulating the patient ‘voice’. Interviewees certainly wanted to give ‘voice’ to their experiences, and felt relief when they were able to ‘get something off their chest’, but this frame was used precisely if and when the preferred frame of ‘conversation’ seemed to fail:

*Sometimes it's been at moments of complete desperation and I haven't got any other platform to turn to in the sense of we're not getting anywhere with the NHS, the funding, we're just constantly having to fight for basic treatment that has been denied for no reason at all. And I've found that it's my way of voicing and feel like I'm being heard, when I'm not being heard when I sit down and speak to someone in person.*

[INQ04; female; early twenties; Post Traumatic Stress Disorder (PTSD) following abuse; feedback provided through blog that was featured on other media; NHS England]

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However, a feedback platform was evaluated especially positively if users received a response that addressed their comments and if action(s) was taken as a result:

*I think getting a response on some level is always important. It's always nice to know you've been heard. I think it's nicer to know you've been heard by people, who have the position or knowledge to act on what you said. [INQ16; female; mid-thirties; multiple long term conditions; very active sharing experiences via blog, Twitter, Care Opinion, NHS websites, Facebook; NHS England]*

People posting online feedback do not want generic public relations style responses (Baines et al., 2018) – what one interviewee called the ‘Teflon technique’. They seek a meaningful exchange with relevant people. And yet, research conducted on Care Opinion found that only 6.5% of the 475 responses analysed were categorised as ‘a transparent conversational response’ (Ramsey et al., 2019). Thus, with notable exceptions, feedback as ‘conversation’ was something interviewees aspired to rather than actually achieved.

By being able to view others’ feedback and relevant responses on sites such as NHS Choices and Care Opinion, interviewees were aware of variations in how different providers within the NHS engaged with online feedback. They evaluated not just the online feedback platform itself, but the relevant healthcare provider as actual recipient as well. Seeing a Trust or GP practice actively engaging with online feedback had a positive influence on how interviewees perceived that provider:

*I feel quite positive about it [Care Opinion] because I feel it does feed into improving services and I like my trust because it is obviously engaging with Patient Opinion.*

1 [INQ17; female; mid-thirties; mental health; active feedback provider using Care  
2 Opinion, forums, Twitter; NHS England]  
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7 Conversely, when a care provider was unresponsive, either directly to the interviewee or  
8  
9 more generally, interviewees were disincentivised from providing feedback in the future, or  
10  
11 looked for alternative feedback routes:  
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17 *I've posted one or two on NHS Choices but my Trust is particularly bad at ignoring*  
18  
19 *them, so it seems pretty pointless doing that.* [INQ20; female; mid-sixties; mental  
20  
21 health and chronic back pain; active feedback provider, has used Twitter, blog, NHS  
22  
23 Choices, other NHS websites; NHS England]  
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29 Inconsistencies and discrepancies between providers' engagement with online feedback was  
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31 deemed especially problematic in the context of the NHS, given the assumption it was meant  
32  
33 to be equal, consistent and available to all, including in how feedback was managed. The  
34  
35 relevance of online feedback for care improvement therefore goes beyond tangible changes  
36  
37 made to care practices. The relationship sought through feedback communications is not  
38  
39 simply the enhancement of existing care relations within the healthcare system. Rather, as  
40  
41 feedback-related communication is itself understood as a vital form of care, it shapes care  
42  
43 relations in new ways. Interviewees' framing of feedback as, ideally, resembling a  
44  
45 'conversation' extended to the form the gathering of feedback took. Free text, narrative  
46  
47 feedback were preferred to checkboxes, surveys and patient satisfaction style ratings. This  
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49 was seen as enabling interviewees to 'steer' the 'conversation' and thus redress some of the  
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51 power imbalances in relationships between healthcare service providers and users.  
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## 5. CONCLUSIONS

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3 Although grounded in their own experiences and as such necessarily personal, the people we  
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5 interviewed provided online feedback in the hope it would improve care for other patients,  
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7 healthcare providers and the NHS more generally. However, the association between  
8  
9 feedback and care improvement took two analytically different, if intertwined, forms. First,  
10  
11 people provided online feedback in the hope it would inform healthcare services and result in  
12  
13 tangible changes to them. Here, feedback served as a *medium for care improvement* (i.e. a  
14  
15 form of advice, suggestion or recommendation directed at the service provider and aimed at  
16  
17 changing care services for the better). For such feedback to be deemed effective, it needed to  
18  
19 be picked-up and actioned by relevant healthcare professionals. Second, regardless of any  
20  
21 actual changes made to services, providing online feedback was experienced by interviewees  
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23 *as participation in care itself* – for example, by helping other patients and their families  
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25 prepare, by making healthcare practitioners feel appreciated, by contributing to a wider  
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27 transformations in the power dynamics between patients and healthcare service providers.  
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38 Building on an understanding of ‘good communication’ as both a crucial precondition for  
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40 good care and ‘care in and of itself’ (Mol, 2008, p.76), online feedback can be understood as  
41  
42 both contributing to care and as care in its own right. The ethics of care foregrounds ‘the  
43  
44 compelling moral salience of attending to and meeting the needs of the particular others for  
45  
46 whom we take responsibility’ (Held, 2006, p.10). Interviewees’ feedback practices were  
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48 shaped by *both* their embodied experiences of care (good and bad) *and* a strong moral  
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50 commitment to, indeed a sense of responsibility toward, other patients and service users,  
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52 healthcare professionals and services, as well as ‘the NHS’ as a highly symbolic national  
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54 resource. They were not just providing feedback on *any* healthcare service, they were  
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56 commenting on *their* healthcare services. Thus, in addition to online feedback practices being  
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1 oriented toward improving care in the two ways mentioned above, these practices should be  
2 understood as acts of care orientated toward care itself– what we refer to as *caring for care*.  
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7 Conceptualising online feedback as *caring for care*, invokes an understanding of care that is  
8 characterised as much by frustration, concern and vulnerability as by love, affection and  
9 nurture (Martin et al., 2015, p. 630). The dual weight interviewees placed on the anonymous  
10 and public nature of online feedback highlights how the personal (and private) and the  
11 political (and public) are closely coupled in online healthcare-related feedback – a point long  
12 argued in feminist care ethics more generally. People providing online feedback in the  
13 context of public healthcare services do so *both as patients* (or family members of patients)  
14 *and as public healthcare citizens*. Following Petrakaki and colleagues (Petrakaki et al., 2021),  
15 we suggest online feedback practices be understood as *productive* of particular forms of  
16 citizenship rather than representative of them. This productive dimension was particularly  
17 evident with prolific feedback providers, whose practices co-evolved overtime alongside  
18 other roles and responsibilities.  
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39 The literature on care has long recognised the mutuality – broadly understood as reciprocity,  
40 mutual influence, interdependency and a sense of common purpose (Brown, 2016) – of  
41 caring relations. However, analytical weight has usually been placed on interpersonal caring  
42 relations or on the practices of those more traditionally thought of as caregivers. We have  
43 drawn attention to how patients and other service users (typically seen as care recipients) use  
44 online feedback to enact care for healthcare professionals and services (typically seen as care  
45 providers). This prompts further questions about different ways patients and the public  
46 perform care for public services (for example, through campaigns, volunteering, bequests and  
47 donations, and so on), a topic that has to date received relatively little sociological attention.  
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1 It is widely acknowledged that digital technologies are changing how care is delivered,  
2 contributing to the emergence of new forms of distal care work (Pols, 2012, Roberts et al.,  
3 2012; Oudshoorn, 2011). A distinctive contribution of the paper is to include writing –  
4 alongside moderating (Ziewitz, 2017, Petrakaki and Kornelakis, 2021) – online feedback as a  
5 form of care work. This is based on the amount of practical and emotional labour that goes  
6 into people’s online feedback practices, but also how these practices were motivated by a  
7 sense of care, commitment and responsibility toward other patients, healthcare professionals  
8 and a ‘national’ healthcare system. This contrasts with an understanding of feedback as done  
9 quickly or even flippantly.  
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24 Acknowledging the labour of providing online feedback highlights the importance of  
25 receiving an appropriate response. While interviewees did value the opportunity to give  
26 ‘voice’ to their experiences, this was not in itself sufficient. Ideally, they wanted feedback to  
27 be a ‘conversation’. Open, publicly available ‘conversation’ was, in fact, a key mechanism  
28 through which they sought to enact care for care, though this, in practice, for the most part,  
29 remained an ideal rather than an actuality.  
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41 One side effect of publicly available online healthcare-related feedback in the UK is that  
42 people can see the responses and assess the relative responsiveness of different healthcare  
43 services. This has consequences for perceptions of and relationships with said service  
44 providers. Given the steady growth in online feedback, this is increasingly pertinent for NHS  
45 healthcare service providers. Currently, it is rare for healthcare service provider responses to  
46 be either conversational or transparent (Baines et al., 2018; Ramsey et al., 2019), and most  
47 healthcare improvement initiatives still rely primarily on solicited survey data (Gleeson et al.,  
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2016). Nonetheless, when taken seriously, online feedback has the potential to tangibly improve care practices and relations (Munro, 2017).

Our analysis has emphasised that, as both citizens and patients, healthcare service users in the UK turn to online feedback to enact care for ‘the NHS’. While our findings are distinctive to the UK and the NHS as a national institution, we hypothesize that elements of them will apply in other contexts where citizens feel both responsible for and dependent on public healthcare systems. Similarly, it is likely that aspects of ‘caring for care’ are present in systems where patients pay more directly for their healthcare, given that here too people develop complex, emotionally charged, often long-standing, relationships with healthcare services, especially in contexts of chronic illness. However, given the importance of situating online feedback practices within *different* contexts and relationships, further in-depth qualitative studies are needed to ascertain what aspects of our findings are particularly pertinent for the wider international phenomena of online healthcare-related feedback. In particular, we would like to see research that interrogates the role different online platforms play in enabling online feedback to be understood as integral to care and, crucially on the perspective of healthcare professionals, institutions, and organisations on this.

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| <b>Gender</b> |             |               |
|---------------|-------------|---------------|
|               | <b>Male</b> | <b>Female</b> |
| 20-35         | 0           | 7             |
| 36-50         | 2           | 9             |
| 51-65         | 4           | 8             |
| 66+           | 6           | 1             |
| <b>Total</b>  | <b>12</b>   | <b>25</b>     |

| <b>Ethnicity</b> |                          |              |
|------------------|--------------------------|--------------|
|                  | <b>White<br/>British</b> | <b>Other</b> |
| 20-35            | 7                        | 0            |
| 36-50            | 9                        | 2            |
| 51-65            | 10                       | 2            |
| 66+              | 4                        | 3            |
| <b>Total</b>     | <b>30</b>                | <b>7</b>     |

**Health conditions and services used** (note that many of the interviewees had commented on or read about multiple conditions and services for themselves and/or family members. The list provided below is based on the *main* condition and/or service they focused on in the interview, which does not mean they did not mention other conditions or services.)

|  |    |
|--|----|
| Multiple complex conditions                              | 10 |
| Mental health  | 6  |
| Cancer   | 4  |
| No specific condition identified                         | 3  |
| Diabetes   | 3  |
| Care of a family member (parent or spouse, not children) | 3  |
| Childbirth (no specific condition)                       | 2  |
| Chronic pain   | 1  |
| Early onset dementia                                     | 1  |

|                                    |           |
|------------------------------------|-----------|
| Heart condition                    | 1         |
| Multiple Sclerosis                 | 1         |
| Osteoarthritis and hip replacement | 1         |
| Spinal problems                    | 1         |
| <b>Total</b>                       | <b>37</b> |

Table 1: Basic participant information (age, gender, ethnicity, health condition, services).

## **CREDIT AUTHOR STATEMENT**

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## **Caring for Care: Online Feedback in the Context of Public Healthcare Services**

### **Highlights**

- Explores the relationship between online healthcare feedback and care improvement
- Focuses on the perspective of people providing online feedback in the UK
- Feedback framed as 'care' and 'conversation', rather than 'choice' and 'voice'
- Foregrounds the (potentially) anonymous and public dimensions of online feedback
- Conceptualises online feedback as 'caring for care' in context of public healthcare