How do healthcare staff respond to patient experience feedback online? A typology of responses published on Care Opinion

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How do healthcare staff respond to patient experience feedback online? A typology of responses published on Care Opinion

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Abstract
Patients are increasingly describing their healthcare experiences publicly online. This has been facilitated by digital technology, a growing focus on transparency in healthcare and the emergence of a feedback culture in many sectors. Due to this area being previously unexplored, the objective of this study was to identify a typology of responses that healthcare staff provide on Care Opinion (www.careopinion.org.uk), a not-for-profit online platform on which patients are able to provide narrative feedback about health and social care in the UK. Framework analysis was used to qualitatively analyse a purposive sample of 486 stories regarding hospital care, and their 475 responses. Five response types were identified: non-responses, generic responses, appreciative responses, offline responses and transparent, conversational responses. The key factors that varied between these response types included the extent to which responses were specific and personal to the patient story, how much responders' embraced the transparent nature of public online discussion and whether or not responders suggested that the feedback had led to learning or impacted subsequent care delivery. Staff provide varying responses to feedback from patients online, with the response types provided being likely to have strong organisational influences. The findings offer valuable insight, advancing the relatively unexplored research area. They also have both practical and theoretical implications for those looking to enable meaningful conversations between patients and staff to help inform improvement. Future research should focus on the relationship between response type, organisational culture and the ways in which feedback is used in practice.

Keywords
Technology in healthcare, patient feedback, online feedback, patient experience, patient satisfaction, patient-centered care, patient engagement, qualitative methods, digital health

Background
Recent UK National Health Service (NHS) policy has focused on a culture-shift towards embracing patients as experts in their own healthcare, with an aim to enable change to be driven by their unique insights. Patient experience feedback is increasingly valued as a relatively low cost indicator to monitor and improve healthcare quality and safety, with its collection mandated across services in the NHS. Further, the digital healthcare revolution is changing the landscape of feedback, providing new opportunities for empowered patients to engage with healthcare staff. Internet use has become a cultural norm in the UK, and whilst healthcare has arguably been slow in embracing technology, patients are increasingly commenting about their healthcare experiences publicly online, similarly to how consumers in many other sectors have been doing for years. Increasingly, the internet is being harnessed alongside the plethora of more traditional tools, such as paper based questionnaires, to gather patient experience data. Online methods of collating patient feedback have distinctive features when compared to traditional forms, including the breaking of geographical barriers, providing the opportunity for honest, real-time and transparent dialogue, and possibly encouraging more patients to provide their feedback. Despite few healthcare professionals asking patients to report their feedback online, some patients are doing so and many are reading online feedback from others. The increase in uptake has been facilitated by the growing focus on transparency in the NHS and a patient desire to provide anonymous, authentic and public feedback, without fear of consequences regarding subsequent care. However, enabling patients to report publicly and anonymously online has raised complex issues, including the paradox whereby patients perceive anonymity to protect against compromising future care, whereas professionals perceive it to be a barrier to effective use and have concerns around reputational damage. Nevertheless, research has supported the validity of online feedback tools, suggesting that NHS ratings are associated with inpatient survey scales and clinical outcomes, Facebook ratings are associated with hospital re-admission rates, and an aggregate of
feedback from Care Opinion, NHS, Facebook and Twitter is associated with Care Quality Commission scores.23

Despite this, the extent to which the full potential of online patient feedback is embraced as a method for quality improvement is unexplored. Research into more traditional forms of feedback suggests that the extent to which staff meaningfully engage with these forms of patient experience is highly variable in practice.21-24 Issues include staff responding defensively, ignoring or being reluctant to believe feedback, and viewing patients as inexpert, distressed or advantage-seeking.25-28 Staff may also believe that directing resources to patient feedback may conflict with the effectiveness or efficiency of clinical care, or cause duplication of work.29,30 Additionally, feedback may also have limited relevance beyond specific aspects of care31, or reach staff months after the care was provided31, making learning less transferable and the wider workforce more difficult to engage.32-34 Despite these challenges, research on the whole suggests that clinicians are generally open, receptive and enthusiastic to learn from patients, but often perceive to have insufficient autonomy or inadequate resources to enact change based upon it, particularly when change is not easily achieved within current systems or ways of working.7-8,35-36

Based on the paucity of research in this area, this study focused on understanding how NHS staff respond to online patient feedback. Specifically, the aim of this study was to identify a typology of responses which healthcare staff working in a hospital setting give to patients providing feedback about their experience of healthcare online.

Methods

Data source
Care Opinion (https://www.careopinion.org.uk) was selected as the data source, offering rich, specific and naturally existing discussions between staff and patients, capturing spontaneity and reducing bias.37-39 Care Opinion is a national not-for-profit social enterprise platform where patients are able to provide feedback regarding health and social care in the UK, and is one of the leading online patient feedback platforms. Care Opinion interoperates with NHS (https://www.nhs.uk/pages/home.aspx), a similar platform provided by NHS England. Despite providing similar services, there are some differences in their offerings (Appendix 1).

Purposive sample
A purposive sample of 486 stories and their 475 responses published during March 2018 were extracted for analysis. The first 300 stories were subsequently published and selected using a representative sampling method. This was supplemented with an additional 186 stories posted via Care Opinion. This was due to the differences between NHS and Care Opinion (Appendix 1), and the implications this may have for response content. In order to achieve saturation in response content, additional Care Opinion stories were selected using the filters available. This included responses within which staff had indicated that a change was planned or had been implemented, and stories which Care Opinion had provided with a range of criticality scores according to policy, ranging from 0-5 (where 0 = no critical element, 5 = highly critical). Stories were limited to those which discussed hospital care due to the specific focus of the research question. The majority of stories included in the analysis received a response (430, 88.5%), with few receiving multiple responses (43, 8.6%). Some of the responses provided did not identify the responder (189, 36.8%). However, of those that did, the majority specified their full name and role (287, 55.3%). Others specified first name only (1, 0.2%), role only (21, 6.0%), first name and role (5, 1.0%) and surname and role (1, 0.2%). Where the role of the responder was specified, a wide variety of job titles and levels of seniority were evident. The majority of responses came from staff working within patient feedback teams (170, 52.5%) or nursing teams (61, 18.8%). Other responder roles included staff from communications teams (8, 2.5%), midwifery teams (13, 4.0%), quality or service improvement teams (9, 2.8%) or service managers (18, 5.6%).

Framework analysis
Stories published in March 2018 and their responses were extracted during June 2018 to allow a reasonable timeframe of 3 months in which to expect a response.40 Framework analysis was used to identify the types of responses provided to online patient feedback following an iterative process.41-42 Initially, data were extracted and read carefully several times to become familiar with the accounts, gain a holistic view and achieve immersion within the data. Reflective and descriptive comments were made and significant extracts were highlighted, making note of initial impressions, commonalities and differences between cases. Data were then coded based on significant and common features of cases, including key issues and concepts, informed by both a priori and emergent issues. Discussion between all authors formed a provisional classification system which was refined via multiple iterations. The framework was then systematically applied to the data, with significant extracts helping to define and evidence each provisional type. Typology titles and definitions were further refined according to scrutiny of deviant cases. In light of each decision, extracts were read to reduce bias and ensure that they were grounded in the data. A matrix was formed which outlined titles, definitions and number of cases. Where it was deemed appropriate, data were coded multiple times. Finally, the titles and definitions of each type were further refined and developed via discussion between all four authors until a consensus was reached. A detailed log of the development and rationale for typology refinement was kept (available
on request from the author). The team comprised four health services researchers, with their disciplinary background being in psychology (3) and sociology (1). Specialist advice was also sought from the CEO of Care Opinion where necessary.

Sentiment analysis
Manual sentiment analysis of all stories was carried out by one author (LR). All stories were categorised according to the writers’ attitude expressed towards their healthcare experience. The majority of stories were classified as positive, where patients had reported only positively regarding their healthcare experience (290, 59.7%). The remaining stories were classified as negative, where patients had reported only negatively regarding their healthcare experiences (115, 23.7%) or mixed, where both positive and negative elements were expressed within their narrative (81, 16.7%) (see Appendix 2 for examples).

Results
Five types of responses were identified; non-responses (56, 11.8%), generic responses (50, 10.5%), appreciative responses (278, 58.5%), offline responses (112, 23.6%) and transparent, conversational responses (31, 6.5%). 424 of the 427 responses included in the analysis were coded according to these five types, and one response was coded twice. The typology of responses is explored in detail below.

Non-responses
A minority of stories did not receive a response (56, 11.8%), and stories prompting a non-response were judged in the sentiment analysis to be almost equally positive (22, 39.3%) and negative (21, 37.5%), with the least amount being mixed (12, 21.4%). Stories fell into this category when a response had not been received within a 3-month period. Response rate between organisations varied widely, with some organisations being overall non-responders. Despite a limited number of users being able to respond free of charge per organisation, of the stories that did not receive a response, the majority were posted to an organisation that did not have a paid subscription with Care Opinion at the time of data extraction. Where stories did not receive a response, Care Opinion indicated that they had often been viewed by staff members, which is suggestive of a more complex and nuanced reasoning beyond a simple lack of awareness of the platform. Despite not providing a public response, it was unclear if staff were able to glean learning from these patient narratives.

Example story: “Hi It is very hard to get in touch with you. I have been ringing for two weeks every day and nobody EVER picks up. Very sad. I am supposed to carry on my physio but how if I cannot even communicate with you? Disappointed.”

Generic responses
Generic responses (50, 10.5%) were mainly prompted by positive patient stories (38, 76.0%), with few being negative (6, 12.0%) and mixed (6, 12.0%). Generic responses took multiple forms. For instance, some organisations crafted two responses, one to be sent to all positive stories and one to be sent to all negative stories. These seemed to have been purposefully designed to appear genuine, yet were copied and pasted regardless of the content of the story.Generic responses often gave seemingly superficial thanks or ‘non-apologies’, without an explanation of what would be done with their feedback, or a vague explanation of how the message would be passed on but remaining unclear around how this would be done, when or to whom. These responses lacked a personalised element, which may suggest that the responder had not fully read, understood or considered what the patient was communicating, or any learning that could be gained from the narrative.

Example response: “I contacted healthy minds and then got a copy of my medical records and it clearly states somebody’s name on my medical record that is her real name. They told me they have tried to change it but their IT system won’t let them. The CEO of both CCG groups know about this but will not do anything about it. Very upset that the people that record on my medical record think this is ok in a modern NHS service.”

Appreciative responses
The majority of responses received were appreciative (278, 58.5%). Stories prompting an appreciative response were perceived in the sentiment analysis to be mainly positive (228, 82.0%), with few being negative (14, 5.0%) and mixed (36, 12.9%). One appreciative response was coded twice. Here responders included a bespoke element, such as personalised well-wishes, reiterations of specific aspects of the narrative or identification of relevant staff members who their story may be valuable to. Responders sometimes retrospectively explained that their feedback had been passed on to specific staff and provided a response on their behalf, however more commonly, responders highlighted that feedback would be passed on in the future. In this instance, it was rarely clear if the feedback had successfully reached the appropriate team or individual, with very few providing follow-up comments. Additionally, thanks and apologies were often given to both positive and negative stories. Thanks were frequently given regarding specific elements of the story, in particular, the boost positive feedback had on staff morale. However, thanks were also given regardless of the story content, but for the time and effort patients had spent articulating their
healthcare experience. In addition, apologies were regularly made where patients had highlighted negative experiences, taking accountability for their organisation falling short of their aims or patient expectations.

Example story: “As soon as you walk into the hospital you are greeted by an amazing reception team. Very friendly and helpful as when consultants run late they keep you very updated. The nurses in outpatient are also lovely and very helpful.”

Example response: “Dear Sir/Madam,
Thank you very much for taking the time to provide us with such pleasuring feedback. We are delighted to hear that our reception team are ‘amazing’ and that you were informed of clinic times throughout. We will, of course, pass this feedback to each of the teams you mentioned, and we wish you well. Best Wishes.” - Small hospital in London.

Offline responses
Offline responses (112, 23.6%) were largely prompted by negative stories (68, 60.7%), with some also being positive (17, 15.2%) and mixed (27, 24.1%). Here staff engaged with patient feedback but were keen to move the discussion offline. Responders prompted patients to continue the conversation via various methods, including some organisations asking all patients to contact the patient advice liaison service (PALS) or patient experience teams, or responders providing specific contact details such as their personal email address or telephone number.

Example story: “My little boy suffered in the hands of hospital staff. He had a major fracture on his hand and was in so much pain & traumatised, hand was swollen. We wait for more than 1hr to be seen. They 1st took an X-ray which showed his bone above his wrist was broken & dislodged. Despite that I begged the staff for pain reliever because my child was constantly screaming and shouting in deep pain we were kept waiting for more than 4hrs. It was more worrying to see that some of the staff could not communicate well!!”

Example response: “Thank you so much for taking the time to write us a comment. We would like to speak with you about the concerns you have raised here. To do this we ask if you could contact us with your personal information and more detail about your visit. Please contact the PALS Team by phone or by email. Kind regards” - Large NHS Trust in London.

Transparent, conversational responses
The least common response type was transparent and conversational responses (31, 6.5%). Stories prompting this response were mainly negative (20, 64.5%), but were also prompted by positive (5, 16.1%) and mixed (6, 19.4%) stories. Here, staff outwardly engaged with patients and embraced the open and transparent nature of online communication. Responses appeared compassionate, recognised the value of patient feedback and delineated a clear plan around how the feedback would have a genuine impact on how care would be delivered subsequently.

Often these responses involved a transparent conversation around the barriers and facilitators to implementing change. Staff tended to communicate the journey that the patient feedback had taken, or more often would take, and provided specific details, with an apparent goal of gaining true understanding from the patient. Stories receiving a transparent, conversational response in the first instance, were the stories most often in receipt of multiple responses.

Example story: “I recently received an invitation to attend a breast screening session. Included in the mailing was a leaflet. On page 7 of the leaflet was the following comment: Some women find the test uncomfortable or embarrassing but remember that the mammographer is a health professional who carries out many mammograms every day.

The two clauses of this complex sentence do not provide the reassurance that I believe the breast screening service is trying to provide. Someone, who in the course of their job carries out a procedure many times in a day, is just as likely to not have compassion for the patient. 1 in 4 women are estimated to have experienced abuse in some form. For many of us, attending procedures such as mammograms or smears is almost impossible because of feelings of shame, embarrassment and humiliation. Rewording this section of the leaflet could go some way to assuring women that their concerns will be understood and accommodated.”

Example response: “Thank you for your post on Care Opinion and your comments regarding the Breast Screening Information leaflet. We are aware that women may feel embarrassed, anxious or worried about the mammogram. Therefore staff will try to make women feel as comfortable as possible, and allay any worries or fears. However, this may not come across in the information leaflet so I will share your concerns with the General Manager for the Breast Screening Service. Kind Regards.” – NHS Board in Scotland.

Example follow up response: “Thank you for your post on Care Opinion. I can confirm that this leaflet is currently being updated and I will share your comments with the review group. Kind Regards.” - NHS Board in Scotland.

Discussion
Our study examining online response types to patient experience feedback contributes to our understanding of the ways in which healthcare staff respond, and advances the relatively unexplored research area of patient feedback published online. The findings suggest that the key variables in response types include the extent to which responses were bespoke and addressed the specific issues raised, and the extent to which responders embraced the transparent nature of online discussion in the public domain. Additionally, the extent to which responders suggested that the feedback led to learning and impacted upon the delivery of subsequent care was diverse. The five response types that were identified were: non-
generic responses, appreciative responses, offline responses and transparent, conversational responses. The most common response types were appreciative (278, 58.5%) and offline responses (112, 23.6%), and the least common response type was transparent and conversational (31, 6.5%).

Our findings raise a number of interesting issues for both research and practice. First, despite being the least common response type, research suggests that transparent, conversational responses are likely to be those most desired by patients. Baines et al. suggests that from a patient perspective, some of the integral features deemed important in an online response to feedback includes detailed introductions, explanations in lay terms, uniquely tailoring the response and providing information for sign-posted services.

A further interesting finding was that the majority of stories which received transparent, conversational responses and offline responses were from patients reporting negatively about their healthcare experiences, while the majority of those which received generic responses and appreciative responses were from patients reporting positively. This may suggest that positive stories are less likely to be utilised for quality improvement purposes, and that negative feedback is perceived to have greater potential to impact the way that subsequent care is delivered. This is congruent with previous research which suggests that staff are often overwhelmed by the amount of positive feedback they receive, making it more difficult to spark meaningful conversation around improvement.

Despite the apparent relationship between story sentiment and response type received, the analysis further suggests that strong, and more complex organisational influences are at play, with organisations often typically responding according a certain response type, or response types. This may be also influenced by the subscription model which organisations adopts when paying to use Care Opinion. Those who do subscribe, do so in various ways, with some organisations enabling all staff to respond to patients, with others assigning certain individuals or teams to respond to all stories regarding their organisation. Enabling all staff to respond may lead to a greater variation in the response type or types provided. However, further research is required to draw conclusions around how these organisational influences are formed, and how both organisational culture and typical response type effects how feedback is used to inform quality improvement work.

The second most common response type provided was offline responses. Research suggests that whilst it may not necessarily be desirable for patients to receive this response due to the requirement to repeat their story, there are various practical reasons for doing so. This includes a more efficient approach, minimising logistical complications when dealing with online feedback amongst the vast amounts of patient experience feedback received. NHS organisations receive patient experience feedback from a proliferation of tools, and in a variety of formats which can be overwhelming for staff. By directing patients to one localised service, the process may become less personalised, but much more manageable. For example, many responders direct patients to the PALS or complaints teams. Often teams who deal with similar challenges, such as quality improvement and patient experience teams, can work in ‘silos’, and may not fully communicate learning around shared goals.

Additionally, staff may be restricted in the response that they are able to give due to Trust-wide policy, resulting in corporate responses.

The findings from this study have both practical and theoretical implications. The typology may serve as a valuable training tool for those staff who engage with patient experience online. Highlighting the key differences may encourage staff to give more bespoke responses and engage in more transparent and open conversation, which has been shown to be valuable to patients. However, whilst one might anticipate that non-responses or generic responses may be less likely to lead to improvement activity than transparent, conversational responses, further research around the relationship between response type and the enabling of learning opportunities is required. Policymakers should also be mindful that patients are increasingly reporting about their healthcare experiences online, and therefore a better understanding around how staff can best respond and harness feedback to provide opportunities to improve the way that subsequent care is delivered is required. Within the context of the patient feedback landscape embracing technology and innovation, the way in which healthcare staff work and think is also required to evolve to ensure efficiencies, expand capacities and extend the boundaries of the ways in which healthcare can be improved. However, without further research, it is difficult to draw conclusions around the impact this will have on quality improvement work in practice.

**Limitations**

As with all research exploring the use of technology in healthcare, users of such services are not necessarily representative of the patient population, with older adults, ethnic minorities and vulnerable patients groups being less likely to provide feedback digitally. Additionally, this study focused purely on the qualitative data available, omitting quantitative information including the 5 star ratings via NHS and the number of responses which had indicated that a change was planned or had been implemented, which may have provided additional insight.

**Conclusions**
In conclusion, the ways in which healthcare staff engage with and respond to patient feedback published online varies, and the response types provided are likely to have strong organisational influences. The findings from this study provide a valuable insight into the types of responses that staff provide to patients online and advance this relatively unexplored research area. The findings have both practical and theoretical implications for those looking to enable meaningful conversations between patients and staff to help to inform improvement and can inform future research to help to optimise patient experience improvement, organisation culture and change, and sustain high performance in healthcare. Future research should focus on the relationship between response type, organisational culture and the ways in which feedback is used in practice.

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### Appendix 1. Key differences between Care Opinion and NHS

<table>
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<tr>
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<th>NHS</th>
<th>Care Opinion</th>
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<tr>
<td><strong>Charging model</strong></td>
<td>Taxpayer funded for all NHS and many independent providers across England.</td>
<td>Uses a ‘freemium’ model, in which providers across the UK can use basic services and with limited users for free. In order to obtain access to premium services (e.g. generate reports and visualisations, increase the number of users) providers must pay a subscription fee.</td>
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<tr>
<td><strong>Story volumes</strong></td>
<td>High volumes as the majority of NHS Trusts and GP practices in England make at least some use of the service.</td>
<td>Story volume varies according to provider use. Premium services are funded at a national level across all NHS Health Boards in Scotland, increasing volume.</td>
</tr>
<tr>
<td><strong>Platform features for story tellers</strong></td>
<td>Enables patients to select a healthcare service and asks for a star rating of healthcare experience, alongside a free-text narrative.</td>
<td>Enables patients to provide a free-text narrative linked to multiple services, and provide tags according to the topic of their story.</td>
</tr>
<tr>
<td><strong>Platform features for responders</strong></td>
<td>Allows one response per story. Responses are automatically signed off from the organisation, although responders are able to detail personal information such as their name and role within the free text narrative.</td>
<td>Allows unlimited responses from multiple individuals and organisations and prompts responders to create a personal profile which appears in responses. Responders may also indicate when change is planned or made.</td>
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Appendix 2. Sentiment analysis examples

Positive example story:

“It has taken us far too long to write this but the passion and sincerity we write it with has only grown with time. The Midwives and Doctors that looked after us were outstanding, from the moment we found out we were pregnant to the moment our daughter was born through to when she was sick and readmitted into hospital. The level of care the staff provided us was amazing. It is really important to us that this feedback is noted and passed onto the teams because we feel so grateful for the care we received. Our midwife throughout pregnancy was kind, knowledgeable and made the pregnancy experience positive and thoroughly enjoyable. The midwife who looked after us for our birth was absolutely wonderful. She made us feel so calm and in the best hands. She is so warm and brilliant at her job. Our daughter needed help to come out and we went into theatre so she could be delivered with forceps. This could have been a terrifying and traumatic experience, but it wasn’t because our consultant doctor was masterful and couldn’t have made us feel more confident about what we were going through. The entire team we had for delivery (2 outstanding and inspirational women) were astonishing. A lady held my hand the whole way. I don’t know what I would’ve done without her. I’m running out of words now but honestly we were so lucky to have been looked after so well. It would mean a lot to us to know this message has been received and that it has been heard - we have names we want to call out but weren’t sure if this was the right place to share them? We are so fortunate to live in this country and to have the NHS. Many, many thanks”

Negative example story:

“I attended for an MRI scan at the mobile scanner recently in the early evening. The member of staff who collected me from the waiting area didn’t greet me, just requested I go with them. We walked in silence outside to a prefab/caravan which was the mobile unit. As we went inside there was another member of staff sitting with their back to me. This member of staff did not acknowledge me the whole time I was there apart from at the very end when they turned and impatiently said ‘you can go now’. Once inside the staff member asked if I had had a scan before to which I replied no. The procedure was not explained to me, what would happen, the different loud noises it makes, how claustrophobic it was, how long it would take or even as I lay on the bed that it was about to move. I was asked if I had any metal on, which I hadn’t however I didn’t feel confident that the staff member had checked as carefully as they should, I had removed all my jewelry however I would have expected them to run through everything possible to make sure I hadn’t missed something.

I had completed the health questionnaire which I am informed the staff member should have gone through each question with me but I was just asked one question and asked to sign. As I lay down the member of staff put a pair of headphones on me (badly) and said something about music but I didn’t hear what was said as my hearing was muffled by the headphones. I was also given a button to press if I wanted to stop at any time however as the bed moved, the wires on the button and headphones must have got caught between the bed and the unit and the headphones pulled off my head and I only just managed to hold onto the button. The member of staff seemed oblivious to this and didn’t even turn round to look at me, just replied ‘3 weeks’ to which their colleague responded it could be 3-4 weeks then carried on doing what they were doing. I let myself out the unit and walked back to the main building alone. I found the whole experience impersonal and non patient centred. The staff were disinterested and almost rude in their approach. The staff need training in customer service/patient care and if compassion could be taught then this wouldn’t go amiss either. I would like this comment raising to the PALS department, reviewed by the Team Leader and fed back to the staff members involved in an attempt for others not to have the same experience.”

Mixed story example:

“I went for a caudal epidural. I was treated by a male nurse, who showed me the utmost respect. Before asking my permission to do any observations he told me his name. I was asked every time if he could take pulse, plus other medical information. I went to theatre and was treated with exceptional care and was told everything that was going to happen. Brilliant care from the team. Once back on the ward, I was in pain, a lady (no name given, but she took blood sugar at start) asked if I needed the toilet, she asked if I could feel my legs to which I replied yes. She then proceeded to rake her fingers up my feet, without asking or telling me what she was going to do. I have Degenerative discs plus Sciatica, I was not impressed, what if she had caused damage. Alas all well, but not a positive thing to do as just had epidural, which already was painful, when patient has spine problems as well as the procedure I had.”