

The Anonymity Paradox in patient engagement: reputation, risk and web-based public feedback

Corresponding Author:

Dr Ewen Speed
School of Health and Human Sciences
University of Essex
Colchester
CO4 3SQ
UK
01206 872847

Co-Authors:

Dr Charlie Davison
Honorary Fellow
School of Health and Human Sciences
University of Essex
Colchester
CO4 3SQ
UK

Ms Caroline Gunnell
Independent Researcher
63 Theydon Park Road,
Theydon Bois
CM16 7LR
UK

Keywords:

Ethics; anonymity; patient engagement;

Word count: 5619

THE ANONYMITY PARADOX IN PATIENT ENGAGEMENT: REPUTATION, RISK AND WEB-BASED PUBLIC FEEDBACK

ABSTRACT

The UK National Health Service has long espoused patient and public engagement. Recent years have seen increasing use of Internet-based methods of collecting feedback about patient experience and public and staff views about NHS services and priorities. Often hailed as a means of facilitating participative democratic patient engagement, these processes raise a number of complex issues. A key aspect of this is the opportunity for comment to be made anonymously. Our research reveals an anonymity paradox whereby patients clearly demonstrate a perception that anonymity is a prerequisite for effective use of these feedback processes, whereas professionals demonstrate a perception that patient anonymity is a barrier to effective use. The risks of anonymity are constructed very differently by patients and professionals. Patients concerns around anonymity were not motivated by a general concern about a loss of privacy, but more that a positive identification might compromise future care. For professionals concerns were voiced more around risks of reputational damage for specific practitioners or practices, (in that anyone could say anything), but also that this anonymous feedback was available publicly and that it might go against the medical opinion of the professional. These concerns pointed to important differences in perceptions of patient and professional vulnerability. In the qualitative analysis that follows the key finding was that while anonymity makes service users feel less vulnerable it can have the opposite effect on managers and clinical staff. This raises important implications for the use and utility of Internet-based methods of collecting patient feedback.

Introduction

For many years, and through several reform processes, the NHS has officially espoused the concept of 'community engagement'^{1 2 3}. Policy and practice in this area falls into two linked, but distinct, fields⁴. Firstly, hospitals, surgeries, clinical teams, providers, monitors and commissioners all gather information relating to 'patient experience' and (at least in theory) use it to improve the design and delivery of services⁵. For example, the 2012 Health and Social Care Act is predicated upon the incorporation of patient experience data into the frontline commissioning decisions made by clinical commissioning groups to ensure the highest quality standards of patient care⁶. Secondly, the NHS uses mechanisms of 'public consultation' or public engagement to gather community views on more strategic aspects of commissioning. These might include such areas as the configuration and location of services, issues over access to care and the setting of local priorities. These two sets of processes are considered in combination to improve the design and delivery of health services, whilst ensuring these services are tailored to meet the needs of the local community.

In collecting data and opinion on public engagement and patient experience, various quantitative and qualitative data collection methodologies have been used^{7 8}. In recent years though, traditional techniques (such as suggestions boxes, paper patient surveys, public meetings and patient forums) have been overtaken by a rapid growth in internet-based mechanisms to facilitate public engagement^{9 10}. Processes and practices of blogging were the social media mechanisms that this particular project was concerned with. Blogs and blogging fundamentally involve placing private content in the public domain¹¹, within varying degrees of anonymity. Blogs have been variously described as 'the new guardians of democracy, a revolutionary form of bottom-up news production and a new way of constructing self and doing community in late-modern times' (p.91)¹². It was this sort of potential that informed the development of the blogging platform in this project; Patient Experience and Public Engagement Blog (PEBL) (www.peblfeedback.com).

Two unique features of the PEBL blog were that it collated open-ended, unprompted feedback and that this feedback was publicly available to anyone with access to the Internet through the blog platform. Patient feedback sites are typically prompted questions in close-ended format¹³.

In contrast to more traditional 'offline' methods, there are four key advantages that blogging offers researchers. First, issues of anonymity in posting content online mean (at least in theory) that bloggers can unselfconsciously write about themselves¹⁴. Second, they provide a publicly available, low-cost and instantaneous technique for collecting substantial amounts of data¹⁵. Our research design was informed (albeit on a smaller scale) by the mass observation movement in the UK¹⁶. Certainly the scope (if not the reality) of blog-based research offers the opportunity for mass participation on a global scale. Third, blog-based research allows for the creation of immediate text, without the need for voice recorders or transcribing¹⁷. Fourth, blogging-based research enables access to populations geographically or socially removed from the researcher¹⁸ (whilst true, this last point is more complex for example across issues or barriers of age in terms of access to the technologies). Unfortunately, whilst these benefits are accrued through online processes of sampling and data collection, the practical application was not as straightforward as this characterization might suggest. Despite the democratic appeal and the promise of mass participation across marginalized groups, the practice of blogging in the context of health and healthcare raised a number of knotty problems. In this paper we address one of those problem areas - around processes of anonymity.

Anonymity in the context of research ethics

Ethical issues surrounding anonymity exist in any research setting where human participants are involved¹⁹. Currently across the NHS, a wide variety of local, national, 'official NHS' and

independent websites and apps are in use, all with differing levels of and relationships with anonymity and personal identification. For example, in a 'traditional' research context, such as a paper-based survey, ethical processes around Institutional Review Boards, coupled to an insistence upon accepted levels of informed consent and anonymity give the appearance at least that research participants can freely participate in ongoing research fully aware of (and having consented to) the risks of identification in taking part in the study. Whilst 'there is no single set of rules or practices that govern the ethics, truth and politics of a research project' (p.107)²⁰ there can be little doubt that the processes that surround NHS research mark a clear attempt to institute a set of research and bureaucratic practices intended to provide a standardized, rigorous governance framework within which UK health and healthcare research can take place, with assured levels of anonymity and confidentiality.

Putting aside the lengthy (and indeed worthy) debates about principles of informed consent²¹, anonymity²², or ethics creep²³, there are other more practical issues that this type of research raises. In the context of a limited and controlled research study where the researcher is the person who directs the data collection process, ethical oversight of the project is relatively straightforward. However, when data collection is opened out into a wider public domain accessible to anyone, then a whole new set of issues arises. Whilst researchers may be bound by ethical guidelines, a blogger may not be. The consequences of a defamatory blog may be both 'professionally and personally ruinous'²⁴. Indeed previous research on a GP population indicated key concerns around the validity of online patient feedback (because of various biases) and the risk of false allegations and confidentiality breaches²⁵. The fact that anyone can blog also raises the issue of moderation. If all blog comments are moderated by the researcher then the possibility for defamatory or unethical blogs are reduced. However, the need for, and presence of moderation in the blogging process introduces an element of control and constraint upon the

principles of participative democracy that blogging purportedly offers. It represents the creep of authoritarian veto into what is and is not 'sayable' within the ethical and legal parameters of the blog.

These tensions between freedom of expression, moderation and anonymity were salient issues in the National Institute for Health Research (NIHR) funded project Patient Experience and Public Engagement Blogging. The aim of this project was to experiment with and evaluate the use of internet blogging platforms to facilitate qualitative methods of patient and public engagement with healthcare commissioners and to incorporate these online methods into novel feedback strategies at a local level. The pilot area of the project was a suburban and rural area in southeast England. Between 2011 and 2013 the PEBL project experimented with an open-access website where bloggers could post blogs about their experiences of care and also offer their views on services in general. All users commented in their own words following their own 'agenda' – there were no pre-set questions or prompts.

Furthermore, the site was open to any and all members of the public and NHS staff. There was no prerequisite need for a referral to the site from a General Practitioner, commissioner or other such health professional operating in a gatekeeper role. Whilst this obviously ceded a degree of control in terms of who might contribute content, it was felt that if the project was to truly try and operate on a principle of democratic engagement then it was necessary that there was no gatekeeper controlling access to the site. In a similar vein, from the outset users were free from any requirement to self-identify in any way; the analytical focus in the project was on what was said, rather than who had said it. This raised a number of ethical and moral conundrums in terms of questions of validity *qua* questions of veracity if the person posting a comment (i.e. the poster) retained their anonymity in any content they posted. On the one hand, this level of anonymity

could be regarded as liberatory, as patients and publics are given free reign to comment, without fear of any negative impact upon themselves or others. On the other hand, it might be regarded as 'one step away from mob rule', where any number of malicious, malevolent or self-serving comments could be publicly posted, with the potential to undermine service delivery, inflict reputational damage on practices or practitioners and bring the very concept of public involvement into disrepute. This tension between the positive and negative potential of 'true' anonymity underscored the project and is a central concern of this paper.

The PEBL project was developed as an investigation into the feasibility and practicality of introducing free text narrative, storytelling and open-ended comment into NHS decision-making. The intention was to generate analytical insights into this free text with a view to providing commissioners with feedback from 'on-the-ground' within their commissioning areas. In order to evaluate the PEBL experiment a set of 41 face-to-face, voice recorded, semi-structured interviews were carried out with PEBL bloggers, patient/community representatives and NHS managers and clinicians involved in commissioning (see Table 1). All interview materials presented here have been anonymised prior to inclusion in the analysis.

In this paper we analyse the data from the evaluation interviews to examine the ways in which anonymity and its attendant risks and dangers are conceptualised on different sides of the NHS/community relationship, i.e. either from the perspectives of the professions or the perspective of patients and members of the public. The evaluation interviews were semi-structured, using a topic guide, but allowing interviewees space to recount their own experiences and views. All interviews were recorded and transcribed. The analysis was a thematic analysis with simple conceptual coding. This coding was conducted by three separate researchers and discussed pre and post-hoc to develop a consensus around the different themes. The researchers used

MaxQDA to analyse the data. In terms of recruitment for the evaluation interviews, lists of all possible participants were collated of all the groups in the research project. Comensurate numbers of participants were selected at random from each list and were then invited to participate in the study. XX were invited to participate, across all groups, and of these forty one actually took part (see table 1). Ethical approval for this study was obtained from Essex 2 NHS Research Ethics Committee (ref: 10/HO302/15). All participants gave informed consent through the standard participant information and consent processes approved by the ethics committee. In the analysis that follows we present the most salient examples here identifying talk about issues of confidentiality and anonymity. The analysis identifies differences across these groups in terms of how they assess and define risks associated with publicity and anonymity.

Table 1. Participants in PEBL evaluation Interviews

Position	No. of interviews
Health Service Manager / Clinician	13
Patient Representative	18
PEBL blogger	10
TOTAL	41

Patient perspectives: 'Anonymity' not 'Identification'

From a service user perspective our analysis highlighted how anonymity in offering feedback was highly prized because of its perceived protective properties. Consider the extract from patient 3 (below) who succinctly makes the case for the benefits of anonymity.

Extract 1

“And I think that’s the benefit that PEBL has – is that there is complete anonymity – and you can be as angry as you want to be, or as complimentary as you want to be, but you don’t have to face anybody and do it”. (PEBL 3, Patient Representative)

Our analysis highlighted how a person making comments about NHS services or sharing their experiences as a patient or carer reported feeling open to a sense of generalised vulnerability. There was a clear perception of a threat of potential victimisation. They feared that, if they publicised critical or negative reports and reflections on care, and were identified as the author, they ran the risk of receiving substandard and delayed care or that services would be delivered to them in a rude or uncaring fashion. Indeed one participant stated this has happened to them in a context where they offered negative feedback on a service when they were not anonymous.

Extract 2

“But yeah, I don’t mind standing up and being counted, right or wrong, you know, but as I say, I think there’s some people that could be ... you know, because there’s always a danger, I think, that if they’re complaining about something, they might end up getting threatened with being thrown off the doctor’s surgery or so on and so forth, or something of that sort – which did happen to me at one time” (PEBL 8, NHS patient – PEBL blogger)

A particularly striking element of this extract is the way a perception of clear and substantive risk, i.e. there is a potential personal 'cost' associated with leaving feedback, that outweighs any perceived benefit. In the context of the medical encounter, where the possibility of sub-optimal attention may be dangerous or even life threatening the risks of giving identifiable feedback outweigh the somewhat distant and possibly impersonal benefits. If the feedback eventually leads to service improvement, this is only likely to happen over a considerable time frame. Any future change is, therefore, only likely to benefit future patients rather than the complainant. Conversely, any perceived or potential negative consequence of that complaint might be much more immediate for the complainant. To be clear, we are not for a moment suggesting that clinical staff will deliver sub-optimal care, rather we are dealing with perceptions and motivations for complaining, on the part of the complainant.

Relatedly, there was a real fear amongst patients and service users that they may be labelled as "troublemakers" or "whingers" and their views may consequently be discounted or discredited. Anonymity was seen as an effective counter to these fears. It is interesting in the following quote that the participants adds caveats about honesty and fairness, responsabilising the complainant to guard against malicious content, almost self-surveilling patient feedback to ensure no undue reputational damage of the professions.

Extract 3

"... if you want to criticise and you're afraid there may be some comeback, then to be totally anonymous, as long as your comments are honest and fair, then yes, ... anonymity in that case is quite good." (PEBL 10, NHS patient – PEBL blogger)

The potential for victimisation was not just something that the patients referred to. The subtlety of the mechanisms that might be involved in the kind of 'victimisation' that service users fear was described by one Primary Care manager in the course of their interview:

Extract 4

(Speaking about NHS clinicians) "Well, they're people. They are people just like you, so if you knew someone had said something about you, and the next time they came in ... hopefully it wouldn't affect how ... you know, your actual provision of the service, but it obviously would colour your tone of voice, ... probably you wouldn't be even perhaps aware of it, or you'd try to cover it up, but it would.....you would still know about that, and even subconsciously it would affect your interaction with that person." (PEBL 6 Patient Experience Manager, NHS Trust)

This manager demonstrates the complexity of the anonymity issue. In this extract, the unstated assertion is that professionals are almost better off not knowing who has complained. The professional perception that public involvement and patient engagement is effectively a negative complaint mechanism becomes apparent. The focus is on what the individual professional response to negative feedback might be, rather than the potential positive impact upon the service provision, based on effective user feedback. In terms of parity, this quote suggests a professional perspective where interpretation of patient feedback is perhaps more negative in terms of implications for the professions. In part this might be explained by a distinction between anonymous feedback on one hand, and the publicly available nature of that anonymous feedback on the other, with little or no opportunity for redress in terms of either potential reputation damage or professional concerns with the medical reporting in these public posts.

Professional perspectives: 'Identification' not 'Anonymity'

The ability for bloggers to remain anonymous meant that the professionals involved reported a fear that the feedback system was potentially open to forms of abuse. For example, people who had never been patients or carers could provide entirely fictitious accounts, identifying incidents of malpractice which could result in reputational damage. This seemed to be heightened in the context of the Internet format, in part informed by concerns around the ability to control and indeed remove content once it has appeared online²⁶. Additionally, professionals expressed concerns about dissatisfied patients with an axe to grind and the potential consequences *qua* reputational damage. However, it should be borne in mind that the PEBL site was not intended as a complaint mechanism, all people blogging on the site were reminded that if they had a formal complaint that they should go through the PALS service. The focus was placed much more on creating an opportunity for service users, public and staff to develop a better service through discussion and exchange of what was working and not working within their service. It was presented as a positive opportunity, but such was the weight of reputational risk, it was hard for the professions to see beyond these risks.

The risks inherent in fictitious and untrue blogs were a concern of a number of NHS professionals who were interviewed. A Practice Manager at a GP surgery summed the issue up like this:

Extract 5

Interviewer: "Do you think that ...you could actually open the whole thing up and just say, "Put your blog on the internet, and tell your story, including naming names", or do you think that the risks of that are too great?"

PEBL 2: "I think the risks of that are too great, because patients don't always tell the truth, at the end of the day. It's very difficult. I mean, I do protect my staff, but I know them as well, and patients don't always tell the truth, they tell you what they think they want you to hear, and they are very very demanding at the moment, they're getting worse and worse, and they know their rights. But I also get a feeling that ... erm ... most, if not all, what people are doing and putting on (PEBL), are truthful." (PEBL 2. NHS Primary Care Practice Manager)

There are a number of tensions outlined in this extract. There is a concern about the veracity of patient accounts, which was coupled to perceptions about a rising sense of patient entitlement, which in turn was aligned with the assertion of patient rights. Within this short vignette it becomes apparent that there is a clear perception of professional and reputational risk as a dominant concern in patient engagement. The motive for these patient untruths is not explicated in the extract, but it is clear that the practice manager regards these processes with suspicion.

In the same interview, the problem of unfair criticism (where a clinical professional has behaved correctly, but the patient is not in agreement) was raised as an associated problem of anonymity.

Extract 6

Interviewer: "And as far as the clinical staff are concerned, then do you think that, again, they would be ... against the idea of people being able to name names?"

PEBL 2 "Absolutely. I don't think they should ... definitely not, because obviously, again, all the clinicians are different, and it could be that, you know, you get Mrs. X coming in to see Dr. Smith, and Mrs. X quite likes being prescribed for all the time, and Dr. Smith doesn't like prescribing, so he says, "Sorry, I'm not going to give you anything. See how you go for a week

and then come back". Well, Mrs. X isn't going to like that, and say, "Dr. Smith doesn't prescribe anything. He's a useless doctor". (PEBL 2. NHS Primary Care Practice Manager)

Again, the dominant perception is of two groups, in direct opposition to each other. The patient group is depicted as uninformed, but also as demanding. Mrs X wants her prescription and does not understand that Dr Smith does not like prescribing. There is a suggestion of a split between a demanding patient and an expert doctor. The possibility of a blog, which allows Mrs X. to share her view of Dr Smith, is unfair (as far as speaker in Extract 6 is concerned) as it does not offer a fair representation of the patient-professional relation and only allows for that relation to be construed in terms of patient entitlement. Again, this is seen to offer the potential for reputational damage. This representation presents a scenario whereby a patient is able to publicly disclose concerns about the medical practices of Dr Smith, whilst Dr Smith is unable to make public judgements about the practices of the patient. As such, the representation points to a democratic deficit for the practitioners, whereby publicity and anonymity create a constraint for the practitioner (bounded by professional codes of ethics) which do not bound the behaviour of the patient bloggers. The blogging makes the professional publicly accountable in a way that the patient is not (and indeed cannot ever be) accountable.

Another interviewee from the NHS management side linked the twin risks of anonymous blogging and un-moderated content:

Extract 7

"Obviously you wouldn't want anything detrimental ... I wouldn't want anything going on there about individual members of staff or anything, really, that could ruin the reputation of the Organisation. I think we've got to be honest, but there are some things that might be – unless

you've got the full picture, and we had an incident ... I don't want to give too much information, there was a really really nasty press story about our Department, about three or four months ago. Now, we all knew that it was rubbish, unfounded, and everything like that, but out there, the population lost faith in this Department. And we were ... you know, you're helplessso I do think there is a risk that sometimes ... unless there is that barrier to protect that, which the press don't have, PEBL obviously seems as though it does, but the press don't – their thing is they're out to sell newspapers, not to serve a purpose - ... So I do think there does need to be some protection, ...” (PEBL 9 Patient Experience Manager, NHS Trust)

In this extract there is an acknowledgement of the need for protection from the potential for reputational damage. There seems to be an awareness on the part of this professional that the motivation behind PEBL is not the same as the motivation behind press stories, but that the dominant view within the NHS trust is not to trust any form of media, be that print or social media. Nonetheless, the need for protection from the potential for reputational damage remains paramount.

From the perspective of the professions, the combination of anonymity for the blogger/reviewer and the identification of places and people providing healthcare opens up the possibility of public feedback mechanisms being used for malicious attacks against service providers. Un-moderated feedback becomes a potential weapon for use in personal vendettas and private retributions. The negative opportunities created by anonymous and un-moderated feedback far outweigh the positives, in fact it was hard to gain any professional input about possible positive benefits.

In terms of reputational issues, the appearance of negative, scurrilous or defamatory stories on the Internet or social media platforms that say things about clinicians and managers may ruin

careers. Not only would this be unfair on the individuals concerned, it could open the way for very costly litigation against the hosts of the blogging site. The 2012 UK case of “mistaken identity” that saw Lord McAlpine defamed on social media (and his use of the legal system to seek redress)²⁷ had a notable impact on some participants’ thinking and discourse on anonymity, identifiability and moderation. The importance of the case in the NHS setting was highlighted by this comment from a PEBL Blogger, who was also active in a local, independent (non-NHS) cancer support group:

Extract 8

“Well, you’ve got to moderate it.....I think it’s essential. Erm ... you’ve seen all the row there’s been in the last few days about ... you know ... Lord McAlpine?...because people can put anything they like on Twitter. PEBL couldn’t be in the situation of me saying, “Dr. So and So is a charlatan” (LAUGHS) it’s not ... you know, whether it’s true or not. It has to be moderated. Yeah, I’m all for that. I don’t like un-moderated news groups of any shape or form. They usually degenerate... it would turn into a bear garden, you know, as you see with other news groups generally.” (PEBL 10 NHS patient – PEBL blogger)

This example highlighted a response to the notion of reputational vulnerability. If the blog/platform was moderated, in order to minimise the risk of reputational damage, then this was more acceptable than an unmoderated ‘free-for-all’ feedback mechanism.

Moderation, ‘anonymity’ and the local

In terms of detailed feedback about health care at a local level, it is difficult to ensure complete anonymity in the sense of making the identity of protagonists ‘unknowable’. Due to the often very idiosyncratic detail of health stories, attendant levels of local details in a submitted blog post may

compromise the anonymity of the patient or carer. This can impact upon anonymity in two main ways. A blog post can function to identify the specific patient to the professionals, based on their knowledge of patients in their practice. This level of detail will not however, necessarily identify the patient to other patients or the wider public because they do not have the same knowledge of the practice patients that the professionals have. Conversely, detail that the way in which the blogger felt their case was dealt with, which identifies specific aspects of the care they received, may well identify the practice to other patients and wider publics aware of the characteristics of that practice, without making the blogger identity known to those wider patients and publics. If feedback is both local **and** detailed, it is highly likely that the people in the story would be identifiable to anyone who had knowledge of the context. This is the case with this blog extract from the PEBL site concerning a GP surgery we have re-named "Great Eastern".

Extract 9

"I would just like to say that the receptionist staff and the dispensary staff at the Great Eastern Surgery are the rudest people. When patients are ill it doesn't help when the staff are so rude and horrible and just plain difficult every time. There seems to be no care whatsoever. One patient came in to say that his wife wouldn't stop vomiting after brain surgery and could a doctor please come out to see her. The receptionist was so rude and dismissive it was unbelievable and all the other patients heard her being rude to this distressed man. The dispensary staff are always especially difficult and unhelpful. There are no smiles and no caring comments. No feeling of care at this place."

Blog from "Patient Force" (<http://www.peblfeedback.com/pebl/rude-and-uncaring-receptionists-and-dispensary-staff/>)

At a theoretical level, such a text would not pass the Pfitzmann and Köhntopp test of true anonymity²⁸. Although a complete outsider would be unable to identify people, anyone who was in the reception area of the Great Eastern Surgery at the time in question would immediately recognise the story, because it is rather unusual and memorable. In technical terms, the individual (the post surgery vomiting woman) is not sufficiently unidentifiable within a theoretical “anonymity set” (which in this case is made up of the patients and staff at Great Eastern Surgery at the time, and, indeed, anyone else who had had the event recounted to them). In the excerpt before moderation, the actual location is mentioned. But even if it wasn’t (as is the case in the post-moderation extract presented above), it could be argued that the patient story seems to be so particular that anybody present or even hearing about it would know exactly who the people involved are. This conundrum raises a number of issues for the moderator in deciding which elements of the blog to publish. As this example shows, questions of anonymity are complex, contextual and need to be considered from the different (and often contradictory) perspectives of patients, carers, professions and a wider public. These groups and interests frequently find themselves in opposition when it comes to both the need for anonymity and the processes that can achieve it.

Conclusions

Our analyses of the PEBL experiment and the perceptions of service users and NHS staff using the site have led us to identify an anonymity/vulnerability paradox, affecting both patients and professionals. Whilst anonymity makes the patients feel less vulnerable to possible negative sanction, it makes the professionals feel more vulnerable, particularly when this feedback is publicly available. This tension speaks to a wider ethics of vulnerability, where professions identify patient anonymity as potentially unfair in that patients can identify professionals and specific

geographical practices, but that professions do not have similar mechanisms to present their own view (they have no right to reply). For professions, this represents a fundamental power imbalance. Paradoxically, patients feel they cannot meaningfully participate in this activity unless they are protected by anonymity. Professionals feel they are reputationally vulnerable to negative patient and public feedback, whereas patients and public feel they are vulnerable to negative quality of care issues if they are identified.

In terms of how this impacts upon the development of web-based healthcare feedback, we propose two solutions to the anonymity/identifiability problem, which are particularly pertinent to processes of open-ended or blog-based feedback (as distinct from other types of 'closed' Inter-based feedback).

In the first type of solution, identity is held "in escrow". In such systems, bloggers have to provide a token of identity (usually a name and an email address) but are assured that their anonymity will be maintained by website moderators/managers. Their identity is then held by the hosts of the blog site, the rationale being that the need to identify yourself to someone will largely prevent the submission of fictitious or untrue material. A major implication of such systems is that users (both members of the public and NHS insiders) need to have complete confidence/trust in the hosts of the site not to publicise their identifiable details. In theory, this approach allows for either self and/or peer group moderation – but only if there is confidence and trust among both the hosts and the users that it is not possible to register with a temporary, fictitious or otherwise untraceable web identity. The scale of the trust issue for both professionals and patients as demonstrated in this paper show that moderation is a massive issue for both groups.

In the second type of solution, no information relating to identity is required. In these systems there is complete anonymity for all bloggers (public and NHS) at the point of contribution. There is no requirement to give any identifying information such as name or email address, nor any need to register. Posting is followed by moderation, which aims to remove offensive material, potential identifying content and fictitious/untrue stories. Again, this means that users need to have a certain level of confidence/trust in the hosts of the site to exercise balanced moderation and good judgement. Even after elements of the text allowing the identification of individuals have been excised, the hosts and users of the site still need to trust that the content of the post is “true”. Even when the risk of reputational damage to any individual is removed by moderation, a lingering suspicion that posts may be frivolous or untrue could remain. Under such systems, the potential for damage to the reputation of organisations and healthcare units still remains. This risk will always be present - unless all identifiable material is removed (including, for example, the names of places, regions, units and surgeries etc.). The implication of this solution might be that bloggers might lose trust for the site as they see information they provided being edited out of posts, which appear on the site. Another key issue in this regard is the impact of purported differences or deficits in medical knowledge between patients and publics. We were not able to detail the implications of this perceived knowledge gap in the current paper and this is an aspect of this issues that merits further research.

In conclusion we note that the non-appearance of the true name of the blogger does not entirely preclude identification, as some stories are so unique as to be recognisable to at least *some* readers. Any system aiming for ‘true’ or ‘total’ anonymity would need also to remove place names, unit names and striking or rare occurrences. If narratives are rendered ‘safe’ in such a way, however, there is a risk that the texts will suffer a major loss of value and impact in terms of service improvement, for example commissioners and service providers will have no idea whether

comments and stories are about “their” services or about services in a completely different part of the country. Consequently they are much less likely to take account of the material than if it were clearly labelled as being relevant to their practice and location.

Central to resolving the anonymity/vulnerability paradox are ideas of trust and notions of a shared goal. In this light, patient feedback conceptualised as contributions to prospective processes of service improvement (rather than retrospective service deficits) may well have a bright future. If professionals, patients and interest groups accept and trust that contributions are intended to improve services, then much of the perceived vulnerability, on all sides, will be reduced. Founding feedback upon a stated commitment to principles of participative democracy, with the mutual responsibility and respect this commands may be an appropriate means of strengthening these levels of trust. A deeper understanding of anonymity in all its complexity can only benefit any and all developments in this field.

Acknowledgements: This research was funded by the National Institute for Health Research under the Research for Patient Benefit Programme (PB-PG-0808-17254).

REFERENCES

¹ Hudson, B, The Value of Public Engagement. *Health Serv J* 2013;123:18.

² Coulter, A, *Engaging communities for health improvement: A scoping study for the Health Foundation*. 2009;London: Health Foundation. Available at: <http://www.health.org.uk/sites/default/files/EngagingCommunitiesForHealthImprovement.pdf> [Accessed 5 October 2015]

³ NHS Choices, *Managing Patient Feedback*. 2013. Available at: <http://www.nhs.uk/aboutNHSChoices/professionals/healthandcareprofessionals/your-pages/Pages/managingfeedback.aspx> [Accessed 5 October 2015]

⁴ NHS Institute for Innovation and Improvement, *The rough guide to experience and engagement for GP consortia*. 2011;London: NHS Institute for Innovation and Improvement .

⁵ Martin, G, P, Representativeness, legitimacy and power in public involvement in health-service management. *Soc Sci Med*, 2008; 67(11): 1751-65.

- ⁶ Speed, E and Gabe, J, The Health and Social Care Act for England 2012: the extension of 'new professionalism', *Crit Soc Pol* 2013; 33:566-76
- ⁷ Bates P, The Role of Stories and Storytelling in Organisational Change Efforts: A Field Study of an Emerging "community of practice" within the UK National Health Service. In: Hurwitz B, Greenhalgh T, Skultans V, eds. *Narrative Research in Health and Illness*, London, BMJ Books 2004: 325-48
- ⁸ Cornwell, J, *The family and friends test: will hospitals raise their game?* 2012;Kingsfund.org.uk, Available at: <http://www.kingsfund.org.uk/blog/2012/06/friends-and-family-test-will-hospitals-raise-their-game> [Accessed 4 September 2012]
- ⁹ White, C. (no date) Using social media to engage, listen and learn. NHS https://www.networks.nhs.uk/nhs-networks/smart-guides/documents/Using%20social%20media%20to%20engage-%20listen%20and%20learn.pdf/file_popview [Accessed 07th Oct. 2015]
- ¹⁰ Patel, S, Cain, R, Neailey, K, Hooberman, L General Practitioners' Concerns About Online Patient Feedback: Findings From a Descriptive Exploratory Qualitative Study in England, *J Med Internet Res* 2015;17(12):e276
- ¹¹ Hookway, N, 'Entering the blogosphere': some strategies for using blogs in social research. *Qual Res.* 2008; 8:91-113.
- ¹² Hookway, N, *ibid.*
- ¹³ Veerhoef, L, Van de Belt, T., Engelen, L, Schoonhoven, L, Kool, R, Social Media and Rating Sites as Tools to Understanding Quality of Care: A Scoping Review, *J Med Internet Res* 2014; 16(2): e56
- ¹⁴ Hookway, N, *ibid.*
- ¹⁵ Hookway, N, *ibid.*
- ¹⁶ Summerfield, P, Mass-Observation: Social Research or Social Movement? *J. Contemp. Hist.* 1985;20(3):439-452.
- ¹⁷ Hookway, N, *ibid.*
- ¹⁸ Hookway, N, *ibid.*
- ¹⁹ Richardson, S, and McMullan, M, Research Ethics in the UK: What Can Sociology Learn from Health? *Sociology* 2007;41(6):1115-1132.
- ²⁰ Soobrayan, V, Ethics, Trust and Politics in Constructivist Qualitative Research, *Westminster Studies in Education* 2003;26(2):107-123.
- ²¹ Faden, R, and Beauchamp, T, *A history and theory of informed consent.* New York. New York University Press. 1986
- ²² Tilley, L, and Woodthorpe, K, Is it the end for anonymity as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher. *Qual Res* 2011;11: 197-212.
- ²³ Haggerty, K, Ethics Creep: Governing Social Science Research in the Name of Ethics. *Qualitative Sociology.* 2004;27(4):391-413.
- ²⁴ Miller, T, Reconfiguring research relationships: regulation, new technologies and doing ethical research. In: Miller, T, Birch, M, Mauthner, M, & Jessop, J. eds. *Ethics in Qualitative Research*, (2nd Ed.), London: Sage. 2012:29-43.
- ²⁵ Patel, S, *ibid.*
- ²⁶ Ronson, J, *So You've been publicly shamed*, London: Picador. 2015.
- ²⁷ Dowell, B, McAlpine libel: 20 tweeters including Sally Bercow pursued for damages, The Guardian 2012, available at: <http://www.theguardian.com/uk/2012/nov/08/mistaken-identity-tory-abuse-claim> [Accessed 4 September 2012]
- ²⁸ Pfizmann, A. and Köhntopp, M. Anonymity, Unobservability and Pseudonymity – A proposal for terminology. In: Federrath, H, eds. *Designing Privacy Enhancing Technologies*, International

Workshop on Design Issues in Anonymity and Unobservability, Berkeley, CA, USA Proceedings,
Berlin; Springer Verlag, 2001;DOI: 10.1007/3-540-44702-4