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‘User generated data’ from online patient forums: Potentialities and constraints for social research

Jeff Bezemer and Myrrh Domingo, MODE, Institute of Education

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Jeff Bezemer & Myrrh Domingo
MODE / Institute of Education, University of London

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Introduction

The relationship between patients and health care professionals has changed significantly in the past two decades or so in the UK and beyond. Today's patients are 'consumers' of 'services' who can read reviews of health care professionals and increasingly also 'performance measures', such as mortality rates of surgeons, before choosing where to go, and 'rate' (Lunich, Rossler & Hautzer 2012) the care they received, on the National Health Service's 'NHS Choices' website and other online spaces. They are also at the same time increasingly recognized as 'experts' in their own right (Fox et al., 2005; Shaw & Baker 2004), who ought to participate in decisions previously made by doctors and other health care professionals alone. Where previously many patients relied primarily on doctors for information about symptoms, conditions and treatments, they now also turn to online health information sites and social networking sites, where they can 'tell their stories' and talk to other patients, discussing experiences, learning from and advising others.

Given the now central role of the internet in healthcare some commentators have started to refer to the contemporary patient as 'e-patients' (Ferguson & Friedman 2004). One effect of the rise of the 'e-patient' is that we now have publicly available, 'user generated', 'naturally occurring', written records of patient's experiences: patient blogs, discussion threads in forums, reviews of services, and so on. These might provide a useful (qualitative) data source for social researchers wanting to investigate the changing patient-doctor relationship – or the ways in which patients portray these relationships, as an alternative or complement to social surveys and focus groups. Research councils, such as the National Data Strategy, encourage research use of such new types of data arising from digitisation (Elias, 2009).

In this paper we explore the potential of online patient forums for research on the patient-GP relationship. As well as adjusting to the 'e-patient' (BMJ 2004), who brings online learning experiences to the consultation room, GPs in the UK are faced with profound changes in the organisation of healthcare. To name a few: GP practices have become significantly bigger, serving an increasingly diverse population, while time available for a consultation has dwindled (now 10-min), and responsibilities of GPs have grown following the introduction of the NHS Health and Social Care Act (2012). This complex environment, in which the patient-GP relationship is now (re)configured, forms the backdrop of online discussions about GPs.

The study is part of a small collaborative project on patients' 'trust' in GPs funded by the Economic and Social Research Council's National Centre for Research Methods. Social survey data analysed as part of this project show that 'general measures' of trust in GPs suggest high levels of trust, while 'specific measures' of trust suggest lower levels of trust, especially among people with certain health conditions (see Stoneman 2014). Wiles (2014) explored this in more detail through focus groups with members of local patient groups, focusing on identifying characteristics people with some of these conditions wanted their GP to have in order to view them as trustworthy. In the present study we explored what users of online patient forums with similar conditions as the

participants of the focus groups write about their GPs and their experiences of care involving GPs more generally, through analysis of discussion threads in online patient forums.

Our interest is in online patient forums as resources for 'user generated data'; that is, records of interactions that were initiated by patients themselves, not by a researcher, as is the case with surveys and focus groups, where patients are asked directly about issues such as trust. Thus we did not aim to explore the potential of, say, doing a 'virtual' focus group in an online forum. We recognize that all three approaches –survey, focus groups, online forums- provide insights in the ways in which patients construct their relationship with their GPs and GPs more generally, as produced in and shaped by different discursive contexts: as a response to a written questionnaire designed by an anonymous researcher, as a response to questions by a researcher and comments by other patients in a face-to-face meeting, or as a response to a written question or comments by other patients. We are not concerned with the 'validity' of patients' accounts, nor with the situated construction of patient-GP relationships in the consultation room, rather we explore the re-construction, interpretation and narration of their encounters with GPs in these different contexts.

We observed two online patient forums, HealthUnlocked (www.healthunlocked.com) and PatientOpinion (www.patientopinion.org.uk). HealthUnlocked provides a discussion space for patients organised in 'communities', while PatientOpinion allows patients to give feedback on services received, which is then relayed to the relevant care providers, who sometimes respond. To contextualise what patients write about GPs in these forums we begin by exploring the aims of those in control of the forums, and the ways in which users ('e-patients') interact in these forums. We reflect on the methodological potentials and constraints of using records of online patient forums as 'data' in the discussion.

Data and method

Sampling of forums

Our study started off with a review of online patient forums. Based on a comparison of their aims, features, and a couple of discussion threads, as well as their accessibility, we selected two discussion forums, HealthUnlocked and PatientOpinion, which differed significantly in those terms. We signed up to each, and familiarized ourselves with the forums in the period between January and March 2013, collecting and archiving screen grabs of the two forums for further analysis.

Sampling of discussion threads

In March 2013 we gathered 29 discussion threads in the two platforms. That is the equivalent of 209 posts. 123 different participants were involved in these discussions. A breakdown for the two platforms is given in Table 1.

	HealthUnlocked	PatientOpinion	Total
Threads	14	15	29
Posts	188	21	209
Participants	101	22	123

Table 1: Sampling

HealthUnlocked

In this platform we selected ‘communities’ to match sampling in the focus group study (Wiles 2014): Parkinson’s Movement, Anxiety Support and Action on Depression. Search terms used to generate related threads within the communities included ‘GP’, ‘doctor’, ‘trust’. Search results were automatically generated by the platform in chronological order with most recent posts appearing first on the list. Further selections were made through a review of the focus of the original post and/or the ensuing posts from participants. For example, posts that specifically discuss GP care or experiences were selected and posts that merely mention GP but focus on other issues were not selected as part of the sample. Sampled threads include the original post and subsequent posts/responses from other community members (see Appendix 1: Sampled Threads). Threads were archived either using Safari WebArchive, Adobe PDF and Microsoft Word to account for written, visual and other modal configurations that were materialised in the online platforms.

PatientOpinion

As this site does not have defined ‘communities’, we used the following combinations of search terms: ‘GP’ and ‘chronic pain’, ‘GP’ and ‘mental health’, ‘GP’ and ‘Parkinson’s’, ‘GP’ and ‘Parkinson’s Disease’, ‘GP’ and ‘dementia’. The same combinations were used with the key word ‘doctor’. Search results were automatically generated by the platform in chronological order with most recent posts appearing first on the list. A further selection was based on the focus of the patient post (title and story post). For example, posts that specifically discuss GP care or interaction during a visit were selected and posts that merely mention GP but focus on other issues were not selected as part of the sample. Posts that refer to general care provided by the overall health care venue were also included, such as a review of the services received at the time of the visit. Sampled threads include the original patient story post and subsequent posts/responses from the health care provider (see Appendix 1: Sampled Threads). Threads were archived either using Safari WebArchive, Adobe PDF and Microsoft Word to account for written, visual and other modal configurations that were materialised in the online platforms.

Ethical considerations

The study was reviewed by the Research Ethics Committee of the Institute of Education, University of London. The main ethical issue we considered was the

status of the posts we aimed to collect. The ESRC Ethics Framework (2010) holds that forums or spaces on the internet and web ‘that are intentionally public’ may be considered ‘in the public domain.’ Therefore they do not expect researchers using these forums to seek informed consent from the authors of sampled posts. Further, the shift to focus on the communication that materialised on the healthcare forums rather than on individual participants complies with code of ethics developed for online research (AoIR, 2002; BERA, 2011). We followed these guidelines, and we contacted the web editors of selected forums to inform them about our research and to seek their permission to use posts from their forum, which they gave. All quotes in the present paper were publicly available at the time of data collection (March 2013), i.e. they did not require signing up (Whiteman 2010). We have removed any real names and usernames. When quoting from posts we have kept the original spelling, but reduced spaces between paragraphs.

Analysis

Analysis focused on a) the design of the platforms and b) the sampled discussion threads. The analysis of the platform design was aimed at gaining insight in the ways in which the two platforms present themselves and how they shape how patients/users interact. It included a detailed analysis of the ‘make-up’ of the platforms, identifying the constituent elements of the main pages and their affordances, as well as the use of colour, image, layout, hyperlinks and other design features (see Appendix 2: Example of PatientOpinion Interactive Icons). The analysis of the discussion threads included 1) a detailed analysis of the generic structure of the threads, mapping the sequential organisation of posts (eg opening post, response to opening post, response to response) and types of ‘moves’ performed in each post (eg recounting event, giving advice); and 2) identification of characteristics attributed to ‘good’ GPs. We also conducted an interview with the web editor of PatientOpinion to verify some of our emerging findings on that platform.

Results

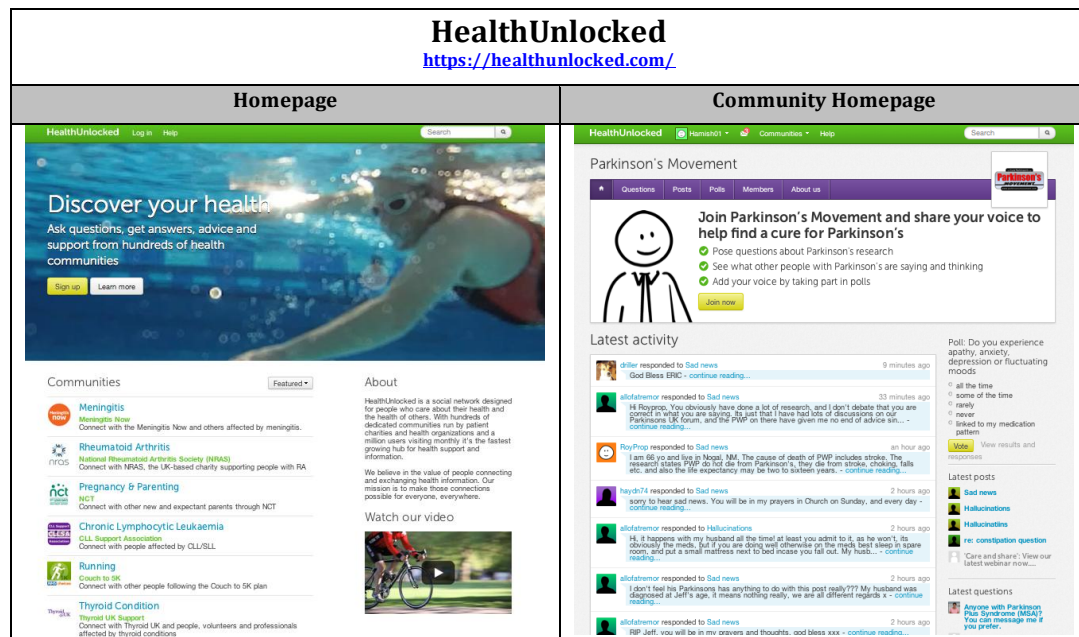
Aims and organisation of the platforms

HealthUnlocked

HealthUnlocked was launched in 2009 by a private company. HealthUnlocked is a social networking site that aims ‘to make health information more personal and intelligent to the needs of the individual’ as the founders believe ‘there is huge social value in people connecting with others and exchanging health information.’ Their mission is ‘to make those connections possible for everyone, everywhere.’ (quotes taken from ‘About Us’ section). On the HealthUnlocked homepage (see Figure 1), visitors are enticed with the following slogan: ‘Discover your health. Ask questions, get answers, advice and support from hundreds of health communities.’ In Jan 2014 there were several hundreds of

communities and 1m users visiting monthly. Each 'community' has its own home page (see Figure 1).

Figure 1: Homepage and Community homepage from HealthUnlocked



Communities may be run by health organisations or patient charities. Members can join and create these communities, enabling them to post responses and start new discussion threads by asking questions. Membership is free. Each member has a profile page that resembles a Facebook page. Visitors who are not a member can follow, but not join discussions. Members have a profile page (see Figure 2: Annotated Profile Page from HealthUnlocked), which can be customised by the user.

Figure 2: Annotated Profile Page from HealthUnlocked

Design Features	Customisable Member Profile Page	Research Potentials
1 pseudonym	1	1 search by name
2 symptoms	2	2 search by symptoms
3 activities	3-5	3 archive of activities
4 questions	6	4, 5 archive of interaction
5 posts	7	6 newsfeed updates
6 newsfeed	8	7 photo/gender
7 photo	9	8 contact by message
8 message	10	9 overview of condition
9 about	11	10 date joined and location
10 joined		
10 location		

The profile page is accessible and visible to all community members and publicly searchable. These pages provide information about the user’s condition, their recent ‘activities’ on the platforms, and date joined. They also include a customizable profile photo, and a link to send a private message. Each member is able to provide an ‘About Me’ narrative to further explain his/her symptoms or share other personal information. In general, patients seem to use the ‘About Me’ section to articulate their personal health concerns.

PatientOpinion

PatientOpinion was founded in 2005 by a GP and is run by a non-profit organisation. A snapshot of their website is included here as Figure 3. As suggested by the slogan, ‘Every voice matters’, the aim of this site is to collect stories about people’s experiences of UK health services, ‘good or bad’, and to make a difference by passing these stories on to the relevant service providers, who can respond. Thus the site is focused on facilitating patient-service provider interaction, not on patient-patient interaction. Indeed PatientOpinion is not a ‘community’ with members, and you do not need to register to write a post.

Figure 3: Homepage from PatientOpinion



Patient Opinion
Every voice matters

An independent site about your experiences of UK health services, *good or bad*.
We pass your stories to the right people to make a difference.

[Information for professionals](#)

Home [Tell your story](#) [About us](#)

[Search](#) Search for stories about...
eg Leeds General Infirmary, heart surgery, depression, S3 8EN

Now my cancer nurse knows she helped me cope

Now the staff know how they helped our family

Now my ambulance crew know the difference they made

Featured stories [View latest stories](#)

"They treated my mum as an **individual** and gave us some **comfort**"
About: Southern General Hospital

STORY HAS A RESPONSE
experienced by 1 other

"Please remember that while I am a patient / **am vulnerable**"
About: Aberdeen Royal Infirmary / Ear, Nose & Throat

STORY HAS A RESPONSE
experienced by 1 other

"I was on a ward with pregnant ladies when my baby was in **intensive care**"
About: Surrey and Sussex, St Peter's Hospital / Paediatrics and St Peter's Hospital / Maternity

Make yourself heard

Whether you're a patient, carer or service user, share **your** story and help make a difference.

[What's your story?](#)

Who's listening to your stories?

73,438 stories told
2,158 staff listening

In the past month...

69% of stories received a response
6% of responses to concerns led to change

The site is organised around 'stories'. Patients and their carers are invited to write their own story; the site offers instructions for how to compose the story, how long it should take to write as well as how it will be circulated. A template allows for the stories to be told in a structured narrative. The following six categories requires a response before proceeding to the next step:

- *What is your story?* (The storyteller will provide a title for the post)
- *What happened?* (The storyteller will describe the experience)
- *Are you....*(The storyteller is given options to identify his/her identity: the patient, a service user, a carer, a parent/guardian, a relative, a friend, a volunteer/advocate, a staff member, other)
- *A bit about your story* (confidential request for postcode, select conditions, tests, treatments as tags for the story)
- *Services your story is about* (add services used and other tags related to the story)
- *When did the story happen* (select story timeframe today, yesterday, last week, last two weeks, last month, last six months, last year, more than a year ago, unknown)
- *Sign and send your story* (a brief explanation of why a story must be signed, confidentially provide an email address and a screen name/not real name, optional email update checkbox, terms of use link, and accept terms and sign the story)

This category is optional:

- *Quick summary* (add keywords to say ‘what was good’, ‘what could be improved’ and ‘how did you feel?’)

Responses to stories are usually handled by a representative of the trust (‘patient experience’, ‘involvement team’). Registration and subscription is optional for health care providers to gain customised access to patient ‘stories’ including delivery options of incoming ‘stories’ to specified personnel and professionals as well as support from the PatientOpinion team.

The main differences between the two platforms can be summarized as follows. HealthUnlocked threads tend to be much longer than PatientOpinion threads: in our sample an initial post in HealthUnlocked attracted 7 responses on average, involving 6 different participants (e.g., other patients, spouses, caregivers), while an opening post in PatientOpinion attracted 1 response on average from healthcare provider/participant (e.g., PALS officer, PPI manager). We have summarized the key features of HealthUnlocked and PatientOpinion in Table 2.

	HealthUnlocked	PatientOpinion
Legal status	Private company	Not for profit organisation
Aim	Sharing knowledge and experiences with other patients	Giving feedback to health care providers
Main participants	Patients	Patients and reps of health care providers
Organisation of interaction	‘Discussion threads’ attached to ‘communities’, consisting of 8 posts and involving 7 different participants on average	‘Stories’ followed by response (i.e. 2 posts involving 2 participants on average).

Table 2: Main differences between HealthUnlocked and PatientOpinion

What do patients and others discuss in their posts?

Across the two platforms we found that opening posts of new threads describe and make judgements about a GP, GP practice, GPs in general, or an event or series of events involving a GP. In HealthUnlocked authors of opening post may also seek advice. Responses typically include expressions of sympathy and empathy. In HealthUnlocked responses also typically include advice and explanation, frequently with reference to the respondent’s own experiences. In PatientOpinion responses typically include an ‘official’ reply, embracing positive feedback and offers to look into negative feedback.

PatientOpinion provides a platform where patients give ‘feedback’ about their GP – that is patients assess/rate/review their GP and/or the service given to them by their GP. Their ‘assessments’ range from ‘positive’ to ‘negative’. The former is illustrated in the following example.

'I am particularly impressed by and grateful for the approach and skills of my GP, Dr M** at ** surgery, **. She referred as planned and the follow up through her has left me feeling reassured about my treatment and the level of care offered. Thank you.' (PatientOpinion, 'Impressed by GP')

The 'Referral and Appointments Centre' responded as follows:

Dear '**',

Thank you for your kind comments, I will share your comments with the practice you have named here, who may wish to write their own response. I am pleased you felt reassured and happy with your treatment.

Best Wishes

An example of a 'negative' experience is the following post:

My mother was badly neglected by her gp, when she finally got through to the GP that her right hip was so painful and she was unable to walk, the gp reluctantly agreed to send her for a x-ray.

"The consultant was shocked by what he had found and it was put down to neglect. My mother was so pleased "at last someone was believing her" but after months of going back and forward, the hospital too began to neglect her. She has sadly lost her fight for life now. I know, and I'm sure that all the stress of both gp and hospital neglect helped towards this (2yrs). I think they used her blood pressure as an excuse to keep cancelling the operation. Cross is not the word I'd use. If there was a problem with her blood pressure, this should have been looked into properly, surely? Why treat people like this? It's disgraceful and I did get into it with the NHS long before she died. They said they would look into it and get back to me. I'm still awaiting a reply. I want this kind of treatment to stop.' (Post 1, PatientOpinion, 'My mothers hip operation')

This post illustrates a more general feature of the online discussions we observed, namely that when GPs are mentioned they often feature alongside other specialists; only some posts are specifically about GPs. The post also illustrates that users of PatientOpinion do more than 'rating' services. The author of this post holds the GP and hospital involved in her/his mother's care accountable for their apparent neglect. Indeed the Trust representative treats the post as a complaint:

'May we first of all offer our sincere condolences for the loss of your mother.

We are extremely saddened to read that you feel your mother had such a poor experience with us. We always take such comments extremely seriously and would always want to investigate thoroughly. We are,

therefore, disappointed to see your comment that you raised the issues with us but that we failed to respond, as agreed. In order we can investigate the issues thoroughly, we would urge you to make contact with our Patient Advice and Complaints Team on 0800 0130018 as soon as possible.' (Post 2, PatientOpinion, 'My mothers hip operation')

Representatives of health care providers typically respond to negative feedback posted on PatientOpinion by apologizing and offering to investigate when patient contacts them. Lacking details of the sequence of events described, and, unlike the patient, bound by institutional constraints on what they can and cannot write about individual cases in public forums (their different roles are also reflected in their different writing styles: with the patient being more 'conversational', and the respondent more 'formal') they can only refer the patient to 'official' procedures for dealing with complaints, away from the online forum.

HealthUnlocked is primarily a 'learning' space: users ask questions and typically get about 7 responses. Here patients' expertise is highlighted. They jointly discuss all aspects of being a patient with the condition that unites them as a community, including symptoms, treatments as well as experiences with GPs and other health care providers and strategies to deal with them. For instance, in HealthUnlocked's Parkinson's community, in response to somebody saying his GP took him off 'B12' one respondent says:

'A lot of people are having to argue for their shots, and are having down time because their doctors do not understand B12 deficiency and PA. [...] Some people with PD also have a B12 deficiency, which can cause fatigue and a whole host of other symptoms, and which is often undertreated or undiagnosed, because few people really understand the condition. The symptoms often get mistaken for other conditions like MS, Fibromyalgia, Chronic Fatigue, etc., which are very hard to treat. At best, when caught quickly enough and treated well, most issues resolve, but it does need regular shots according to the individual need of the patient.' (Post 5, HealthUnlocked, 'How difficult is ti')

Another thread from the Parkinson community opened with the following call for help:

'Help please. Head tremor many years, jaw movement 2 years. Slight tremor mainly left arm. Some tention now noted upper body... Stressing me now. Dr no help...says would be in arms and short steps if Parkinson mind you hasn't seen me at worst. (Post 1, HealthUnlocked, 'Help please')

One reply reads

The following are just some of the things your GP should consider. Has your GP asked about your sense of smell. Apparently this is likely to be one of the first symptoms. Are you unaccountably fatigued by little exertion. Drooling / dribbling. What about muscle stiffness, particularly in

the torso when bending , cramps, slow movements. Is it somehow more difficult to get out of a car. Maybe turning over in bed is a bit more awkward than it was. Has your handwriting started to become largely illegible. Are you unaccountably depressed or perhaps you experience anxiety when normally you would not. Do you find yourself misjudging the space available to get through perhaps banging your shoulder into a door frame. Do people ask you to repeat yourself as your voice is very soft. Dry skin and here's a funny one increased dandruff. Vision problems, blurred vision, difficulty focusing and one i have that I particularly dislike is eye convergence insufficiency which leaves me with double vision for much of the time. One test commonly tried by neurologist is to get the patient to tap the first finger and thumb together for as fast and long as possible, a PWP will soon start to falter or slow a lot. And there's more but that's enough for now (Post 10, HealthUnlocked, 'Help please')

In this instance, HealthUnlocked operates as a 24x7 service where fellow patients display many of the characteristics they are looking for in GPs (see next section), including time, attention and availability, as well as diagnosis (see Giles & Newbold 2010 for an account of self- and other-diagnosis on a discussion forum for mental health patients). Note, however, that while the responses to the 'help' call above suggest a certain 'expertise' and 'authority', authors often also include disclaimers, such as 'I am not a doctor, but...', to confirm that their advice has no 'medical' status.

As in PatientOpinion users in HealthUnlocked also make judgements about GPs, but these too prompt discussions about what to do about it (alongside expressions of sympathy), as in the posts discussed above. For instance, in the Parkinson's community, one member writes:

He placed me on patches and said I'll see you in 3 months. I lose my voice and choke, explained my issues and he did not even respond! Do many of you have Dr.s such as mine?
(Post 1, HealthUnlocked, 'My Dr is short with explaining anything')

Another member replies:

I had the same problem with my doctor. My suggestion is that you see if you can find a Movement Disorder Specialist in your area. I found one by contacting my local Parkinson's support group and asking for a recommendation. At the very least get a new doctor. There's no reason you should be treated that way. Blessings.
(Post 2, HealthUnlocked, 'My Dr is short with explaining anything')

In an discussion thread from the Depression community patients were also giving and seeking advice on how to deal with GPs:

'No, you're not being negative, just expressing how you are feeling at the time. It is depressing to have to wait weeks for an appointment only to

find that when you do see a GP they have such a short time that there's hardly time to think. GPs vary so much. I used to live in a middle class area where the GPs were superb, I always felt understood and although the appointments were no longer I did feel listened to and understood. Now I find sometimes I feel supported by one particular GP but other times I feel like an object to be quickly assessed and shoved out of the door again - it's a much poorer area and GPs are overworked locally. I find it helps if I think clearly beforehand about what I am going for and make bullet points which at least enables me to make sure I don't find I've left without saying something. GPs tend not to like that approach but I find it helpful. The other thing I find it to think about their role - I feel that my GPs do not consider themselves as there to talk to, so when I need someone to listen I don't look to the GP for that, I either turn to someone else, a friend, this website, a therapist I see privately (luckily I can afford that) or I would ask the GP to refer me to a counsellor or contact an organisation like Mind. My experience has been that in recent years most GPs simply don't have the time or inclination to listen like a counsellor even for a short time. It all depends what you want from them. I do find it helps to be clear in my own mind what I am hoping to get from them and once I know it's reasonable to expect that from them then to communicate very clearly, so having something written down helps.'

Suexx (Post 6, HealthUnlocked, 'GP visits')

What transpires from these posts resonates with Wiles' findings about the 'professional patient', i.e. patients who have developed knowledge about their condition as well as skills to deal with health services and maximize the care they receive. Forums such as HealthUnlocked enable newly diagnosed patients to learn from these professional patients. Thus the posts highlight the range of different functions served by HealthUnlocked (as opposed to PatientOpinion, where the focus is narrower), with members providing peer support and recognition and quasi-medical advice, as prior studies have highlighted (Giles & Newbold 2010; Gavin, Rodham, & Poyer, 2008; Horne & Wiggins, 2009), but also strategies for dealing with healthcare professionals, systems and procedures.

What do patients write about their GPs?

Users of the forums refer to a range of knowledge, skills, attitudes as they make varying judgements about a specific experience with a GP, or about their GP or GPs more generally. Here are some examples of each:

'GP services and our local Ayr hospital were very satisfactory. People cared and communicated. I felt my husband was well looked after. The consultant Mr *** was superb and all that a doctor should be. He went the extra mile and treated us all with respect.' (Post 1, PatientOpinion, 'My husband's care')

'My mother was badly neglected by her gp, when she finally got through to the GP that her right hip was so painful and she was unable to walk, the gp reluctantly agreed to send her for a x-ray.' (Post 1, PatientOpinion, 'My mother's hip operation')

'The GP had prescribed the wrong drug' (Post 1, HealthUnlocked, 'bad management and poor care.')

'I feel I know what he is doing' (Post 7, HealthUnlocked, 'How difficult it ti...')

'Sometimes feel that GP is fed up of seeing me (Post 1, HealthUnlocked, 'GP visits')

'I have a great relationship with my GP practice' (Post 5, HealthUnlocked, 'GP visits')

'he is genuinely interested in me as a person' (Post 7, HealthUnlocked, 'How difficult it ti...')

'Unless you have a very poor GP you are likely to find him or her supportive and understanding' (Post 5, HealthUnlocked, 'Scared to speak')

We did not find any examples of comments about GPs more generally in PatientOpinion: in this space users comment about specific GPs, as suggested by the forum. Some posts are more explicit about what is expected from GPs than others. Yet what transpires is that the following characteristics are valued in a GP: Showing respect, dignity, and understanding; taking time, going the extra mile, and being a good listener; providing support and care, being knowledgeable and ('genuinely') interested in the condition user suffers from, such as Parkinson's, – including diagnostic skills, knowledge about treatment options, providing prompt referrals and accurate prescriptions.

Patients also recognize the boundaries of a GP's responsibilities and capabilities. One patient writes:

'I think of a GP as more of a 'starting point' to direct you to the right place' & 'I know my GP can't "really" help me that I have to help myself but at least I know it's a "lifeline" if I need one.' (Post 6, HealthUnlocked, 'Scared to speak')

And they recognize the limits to what GP can do within the health care system. A discussion in the Parkinson's Community starts with the following post:

He placed me on patches and said I'll see you in 3 months. I lose my voice and choke, explained my issues and he did not even respond! Do many of you have Dr.s such as mine?

One respondent includes a video of a TED talk by a GP titled 'from God to guide'. Another participant then writes,

The video that ** sent is very good. It addresses the patient / dr. relationship and acknowledges that dr.s need to communicate and work more together with the patient. However, IMO, I believe that it is not enough. I think the medical system and healthcare is out dated, especially in treating illnesses such as Parkinson's. More and more, it is evident that the dr.s are helpless and lack more information to treat Parkinson's effectively. (Post 12, HealthUnlocked, 'My Dr is short with explaining anything')

The issue of time also comes up, and is often associated with limitations of the healthcare system, not with shortcomings of the GP. These comments resonate with Wiles' (2014) findings in relation to the 'context of trust'.

The online discussions in HealthUnlocked also suggest that patient's perceptions of their GP shape their decisions about what action to take. One member of the Depression Community writes

'My question is should I go speak to my GP who I feel does not have much time for me with the problems of Fibro too or should I wait & tell my Community Psychiatric Nurse when I next see her on 21 March.' (Post 1, HealthUnlocked, 'Should I admit the truth')

One of the replies to the 'Help please...' post discussed above gives the following advice:

Keep a detailed daily log with your symptoms and get a referral as soon as possible to see a neurologist with your log. Good luck. (Post 6, HealthUnlocked, 'Help please')

The author of the opening post replies:

'Good idea never thought of that Trouble is gp will say am being neurotic.' (post 9, HealthUnlocked, 'Help please')

These posts indicate that patients anticipate how their GPs might respond to their 'story', and sometimes worry that they will not be understood or given the time to explain themselves.

Discussion

'Trust' has been described as being fundamental to the patient-doctor relationship as there is an element of risk and unequal knowledge between parties. This has been shown in social surveys (Stoneman 2014) and focus

groups (Wiles 2014), where patients were asked about trust directly. Yet in the discussions between patients and representatives of health care providers about GPs in HealthUnlocked and PatientOpinion we did not find anyone using the notion of trust to describe the doctor-patient relationship. However the picture they sketch of a 'good' GP is similar to what transpires from Wiles' focus groups: displaying empathy and support, giving time, listening and possessing knowledge about specific conditions are qualities that are valued in both studies. Thus the notion of trust may be a useful sensitizing, theoretical concept, and a useful concept to elicit discussions about GP-patient relationships, yet it has limited phenomenological relevance.

As with the interpretation of any data its context of production should be accounted for. The online spaces where we collected our data shape what patients say about GPs, in different ways. PatientOpinion serves as a public complaints and appraisal platform, prompting a particular form of interaction between patients or their carers and representatives of healthcare professionals. In this public space, responses by the latter are constrained by institutional roles and responsibilities. HealthUnlocked enables patients to form virtual patient support groups or 'communities'. These (international) communities provide what some patients say they do not get enough from their GP: 'understanding', 'support' recognition, as well as specialist knowledge about certain conditions and ways of dealing with the shortcomings of the healthcare system (eg the 10min slot) and/or GPs (eg their lack of knowledge about say Parkinson), and round-the-clock availability.

While these spaces are worthy of investigation in their own right, as sites of communication, learning and identity formation (cf. Giles 2006) we also found that they provide limited opportunities to address specific, pre-defined questions. One constraint is that when working with 'user-generated data' to address such questions, as opposed to using data produced through elicitation (as in interviews and surveys) sampling relevant data becomes an issue. Both HealthUnlocked and PatientOpinion offer a search option, but key terms, such as 'GP' and 'trust' yield numerous irrelevant threads (the organisations providing local healthcare services in the UK on behalf of the NHS are called 'Trusts'), and what you're left with is a wide variety of different threads: In some the GP may only feature tangentially, and in others the GP may be the focus of the posts. Another constraint is that we have limited contextual information. While in HealthUnlocked some information may be gleaned from members' 'profile pages', overall we do not always have access to people's country of residence (which in the case of HealthUnlocked was not limited to the UK), gender, age, ethnicity and other background characteristics are personal information members can opt to disclose publicly or keep private in the online healthcare forums. Thus we weren't able to explore associations of trust attributes with other characteristics of individuals (eg age, gender), something that the survey and focus group can. Nor were we able to clarify what authors write (eg whether or not they were referring to their GP when writing 'doctor').

The two platforms we explored come with distinct possibilities for sampling. 'Stories' in PatientOpinion are relatively more structured than discussion

threads, and PatientOpinion staff review and attach additional relevant tags to them, facilitating searches. Yet when the research interest is in specific patient groups HealthUnlocked provides better inroads, as it is organised around communities usually defined in terms of a specific condition. As it's focused on stories PatientOpinion provides 'specific' measure of trust, while HealthUnlocked also enables 'general' discussions about trust in GPs; though we didn't find any specifically about 'trust', we did find that users make generalisations about GPs. The interactional nature of threads in HealthUnlocked enables a range of conversational exchanges to transpire within one thread. In contrast, the PatientOpinion platform tends to have less conversational exchanges per thread and more formalised feedback. However, both online platforms provide possibilities for researching patients' experiences with their GP.

We conclude our reflection on the potentials and limitations of using online forums as data sources by comparing them with focus groups.

	Online forums	Focus groups
Data collection	- Publicly available - Free to use	- Requires substantial effort and funds
Research participants	- Limited background info - No informed consent	- Background info can be collected - Always informed consent
Context shaping data	Platforms run by third parties	Focus group run by researcher
Researcher participation in discussion	Researcher not a participant, so can't steer	Researcher is participant, steers discussion
Mode of discussion	Online writing	Face-to-face communication
Selection	Researcher selects relevant posts and quotes from digital archive	Researcher selects relevant extracts from transcripts

Table 3: A comparison of using online forums and focus groups for research purposes

In conclusion, we propose that while focus groups may be the better suited approach for exploring specific concepts and questions ('what are characteristics of *trust*?) with specific patient groups, online forums are suitable resources for exploring what patients themselves identify as key issues and questions and how they among themselves portray their experiences with health care and health care professionals. One topic frequently addressed in online forums, and not so much in focus groups, is ways of dealing with GPs and other healthcare professionals. At the same time, the notion of 'trust', which is used by social scientists to describe GP-patient relationships and prompt accounts from patients did not emerge as a key category in the 'user generated', self-directed discussions we observed. This we believe is an important potential of user-generated data in digital environments.

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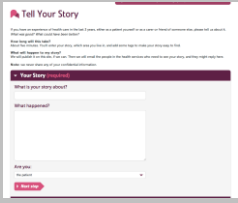




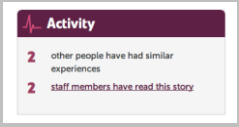
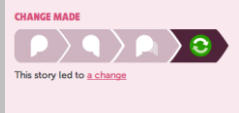


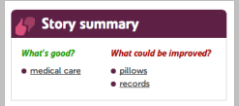
Appendix 1 Sampled Threads

The following conversation threads and their corresponding posts were sampled from HealthUnlocked and Patient Opinion.

HealthUnlocked https://healthunlocked.com/	
Sample	Thread Title
1	HOW HARD IS TI TO GET NEW G.P .IN THE UK ONLY
2	Trust
3	Help please. Head tremor many years, jaw movement 2 years. Slight tremor mainly left arm. Some tention now noted upper body...
4	Bad management and poor care.
5	My Dr. is short with explaining anything.
6	How am I suppose to cure my anxiety if I can't go to the doctors
7	Doctors
8	Doctors "dismissing" you if you have/had MH Problems!
9	Stressing out after Doctors visit, but should i??
10	Sympathetic doctors
11	Scared to speak to my doctor
12	I don't feel my doctor understands me, what can I do next?
13	Should I admit the truth to my GP or CPN?
14	GP visits
PatientOpinion https://www.patientopinion.org.uk/	
Sample	Thread Title
1	On my third waiting list for mental health problems
2	My husband's care for terminal pancreatic cancer
3	My mother's hip operation
4	Care, dignity, kindness and respect
5	mental health and A&E
6	I am very pleased with my GP
7	Inpressed by GP at Looe surgery
8	An amazing GP support team
9	treated with dignity by consultant at clinic
10	Person with Parkinson's in hopsital
11	3 week stay at Lymmington
12	Mum's last days were as good as they could possibly be
13	My experience of understanding Parkinsons
14	Superb nursing, very poor communication
15	111 – a good service, and a question

Appendix 2 PatientOpinion Interactive Icons

There are three primary icons used on the site and they indicate a particular type of social and textual interaction on the site: prompt/invitation to participate, read and relate/reply. The textual and/or social interaction supports the aim of the platform to raise awareness and prompt change in the healthcare service for improved patient care.

Icons and Social Interaction	Prompt/ Invitation	Read	Relate/ Reply
 <p>Indicates 'conversations' such as a patient posting a story and providers responding to the story</p>	<p>'Tell your story'</p> 	<p>'Story has a response'</p> 	<p>'Responses'</p> 
 <p>Indicates statistical information on how many professionals read the story and how many other patients support the story by sharing a similar experience as well as how these combined activities prompted a positive change in the healthcare service</p>	<p>'Who's listening to your stories?'</p> 	<p>'Activity'</p> 	<p>Response and Support Leads to Change in Practice</p> 
 <p>Indicates feedback provided about a healthcare service experience; shows support about someone else's story by sharing a similar experience</p>	<p>'This week: what are people saying?'</p> 	<p>'Story summary'</p> 	<p>'Show your support'</p> 