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## Combining patient talk about internet use during primary care consultations with retrospective accounts. A qualitative analysis of interactional and interview data

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#### ABSTRACT

Despite widespread acknowledgement of internet use for information about health, patients report not disclosing use of online health information in consultations. This paper compares patients' reported use of the internet with matched video recordings of consultations. The concepts of doctorability and epistemics are employed to consider similarities and differences between patients' reports in interviews and actions in the consultation. Data are drawn from the Harnessing Resources from the Internet study conducted in the UK. The data set consists of 281 video-recorded general practice consultations, with pre-consultation questionnaires completed by all patients, interviews with all 10 participating doctors and 28 selected patients. We focus on the 28 patient interviews and associated consultation recordings. A conversation analytic (CA) approach is used to systematically inspect both the interview and consultation data. In interviews patients presented use of the internet as associated with appropriate self-management and help-seeking. In consultations patients skilfully translated what they had found on the internet in order to provide grounds for the actions they sought. We conclude that patients translate and utilise what they have found on the internet to assert the doctorability of their presenting problems. Furthermore, patients design their talk in both interviews and consultations to accord with their understanding of the epistemic rights of both doctors and patients. Patients search the internet so they are informed about their medical problem, however they carefully manage disclosure of information to avoid disrupting the smooth running of medical interactions.

Discussion of the potential benefits, as well as issues, arising from use of the internet for health is evident across the Western world (NBC news online 2019; Alves et al., 2019; Mail Online 2017). In 2019 93% of UK households had internet access, and 63% of adults reported using the internet for health-related information - an increase of 9% from the previous year (ONS 2019).

Ever-increasing access to medical information via the internet raises questions about the effects on medical practice. Nettleton and Burrows (2003) pointed out that as clinical decision-making is increasingly rooted in health 'intelligence' from information science as opposed to practitioner intellect, medical knowledge can be seen to have been dislodged from its 'traditional' institutional base. Nettleton further

contends:

Rather than being concealed within the institutional domains of medicine, knowledges of the biophysical body (hitherto medicine's most sacred object) seep out into cyberspace. (Nettleton 2004:674)

The internet provides access to a wealth of information intended for healthcare professionals and the public as well as material produced by and for patients (Ziebland and Wyke 2012). However, interview studies suggest that patients often refrain from disclosing their use of online health information in consultations (Bowes et al., 2012; Stevenson et al., 2007).

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Patients' decisions about whether, when and how to disclose use of information from the internet in healthcare consultations is rooted in the classic notion of the 'double-bind' (Bloor and Horobin 1975). Patients are expected to be sufficiently knowledgeable to make the decision to seek care, but once inside the consultation are expected to defer to medical wisdom. It is important to note that the 'double-bind' is not invoked here to suggest that doctors act in a paternalistic way but rather as a comment on the complex work required of doctors and patients in consultations to manage asymmetries in medical interactions.

Hesitancy is also evident in doctors' discussion, and use, of information from the internet in consultations. Stevenson et al. (2019) developed and extended Nettleton's (2004) work on 'e-scaped medicine' to argue that Internet resources may be 'recaptured' by doctors, with information transformed and translated into a medical offering. They argue this maintains the asymmetry between patients and practitioners necessary for the successful functioning of medical practice.

One approach to understanding the effect of the increase in access to medical information from the internet on doctor-patient communication is to undertake detailed study of the social organisation of patient-practitioner interactions (Robinson 2003). Patients are conscious of the need to be 'responsible' users of health care services (Ziebland et al., 2019) and to justify seeking medical assistance in the consultation by projecting that the problem is worthy of the doctor's attention and professional help is warranted. Heritage and Robinson (2006) described this as patients seeking to establish the 'doctorability' of their presenting problem. The notion of doctorability is a useful lens through which to consider patients' accounts of use of the internet before, and actions within, consultations.

It is also important to take account of how doctors and patients manage discussion in accordance with their epistemic status (Heritage 2012). Epistemic status refers to what participants in any interaction know and don't know, how much they know relative to each other and what they are entitled to know. As Landmark et al. (2015) point out, patients have primary epistemic rights to knowledge about their experience of symptoms, preferences and life-world circumstances, while physicians have primary epistemic rights to knowledge about diagnoses, appropriate treatments and so on. The internet blurs these boundaries by widening patients' access to information that is broadly in the medical professional's domain and vice versa. This has the potential to challenge traditional epistemic boundaries/rights to knowledge.

This paper presents an analysis of interviews with patients in which they report use of the internet before consulting their doctor, combined with video recordings of their actual consultations. We use a conversation analytic (CA) approach, focusing on the concepts of doctorability and epistemics, to consider how patients' accounts of references to the internet in consultations compare with data from their consultations in which use of the internet was raised.

## 1. Methods

This paper uses data from the Harnessing Resources from the Internet study (Seguin et al., 2018). The data set consists of 281 video-recorded general practice consultations, with pre-consultation questionnaires completed by all patients, interviews with all 10 participating doctors and 28 selected patients. Participating practices varied in size and urban/suburban/rural classification across London and the southeast of England. The overall aim was to gain insights into perceptions about, and use of, the internet in primary care consultations.

Pre-consultation questionnaires were completed by patients immediately before their consultation. These included questions about whether they had accessed any information related to their health problem or concern before their consultation (carefully avoiding specific focus on the internet). Further details about recruitment and data collection are provided elsewhere (Seguin et al., 2018) On average, we recorded six sessions (half days) per doctor to reach our target of 30 consultations per doctor.

We selected between three and five patients per practice for a postconsultation interview based on one or more of the following criteria: (i) patients reported searching the internet before their consultation and this was raised in the consultation, (ii) patients reported searching the internet before their consultation and this was NOT raised in the consultation, (iii) patients raised the topic of the internet in the consultation and this was not reported in the pre-consultation questionnaire and (iv) doctors used the internet or raised it as a topic during the consultation. We aimed for maximum variation in terms of sociodemographic characteristics. Face-to-face interviews were conducted by one of two researchers. On average interviews lasted 1 h and were audio recorded. Patients were asked about use of information sources before the consultation and discussion of the internet in the consultation. Post-consultation interviews with all ten doctors asked about patients' and their own use of the internet to inform consultations. As the focus was on patients' use and discussion of information from the internet, analysis of the doctors' interviews is not included in this paper.

#### 1.1. Analysis

We integrate interview and consultation data; an approach which Collins (2005) argued has the potential to illuminate analysts' interpretations. In combining data we used a conversation analytic (CA) informed approach to systematically inspect both consultation and interview data.

CA is concerned with the social scientific understanding and analysis of interaction (Maynard 2012) and is a well-established method for analysing naturally-occurring institutional encounters such as communication in health care (Leydon and Barnes 2020). Analysis of qualitative interview data is usually content based (e.g. thematic). However, interviews are another form of institutional interaction and, as such, attention to the social organisation of interaction here can help us to understand how issues such as identity, responsibility and agency are interactionally accomplished (Wooffitt and Widdicombe, 2006).

This 'borrowing or combining' of approaches to analysis is akin to the work of Stivers and Timmermans, who describe their analysis of consultations as neither conversation analytic nor ethnographic but representing a blend akin to microethnography (Timmermans and Stivers 2017; Stivers and Timmermans 2016). Our approach adopts the key elements of a conversation analytic approach, while remaining aware of the limitations of combining naturally-occurring (consultation data) and data from interactions created for the purposes of the research (interviews).

Although not naturally occurring data, interviews are interactional data with consequences for how such data should be understood (Potter and Hepburn 2005, 2012). Therefore, we listened to the interview (as well as the consultation) data and did not rely solely on transcriptions. We have provided details of how interviewees were selected, by whom they were interviewed and the focus of the interview. We used line by line analysis to consider not just what people said in accounts of use of the internet but also how they produced and presented these accounts. We included the interviewer's question to provide access to the sequence of the interaction upon which our analysis is based, as well as line numbers to signpost evidence for our analytic claims. Data are also presented with some details beyond the conventional orthographic representation of talk, such as cut offs and restarts.

Sections in the video-recorded data relating to the internet were selected for additional transcription using the Jeffersonian system (Jefferson 2004), which includes details such as overlaps in talk, pauses, emphasis on particular words and changes in the tempo of interactions. A key to the notation is shown in Fig. 1. The additional transcription facilitated conversation analysis (CA) to consider how actions were constructed and produced in the consultations (Sidnell, 2010).

Ethical Approval was obtained from a local UK NHS Research Ethics Committee, and governance approval from the Health Research Authority.

#### **Transcription symbols**

- Overlap onset ſ Overlap offset (0.2)Pause in tenths of a second (.) micro pause > < rapid speech (())text between double brackets gives descriptions of action or clarification of phonetic meaning Extended vocal sound. Multiple colons indicate further extension ? Upward intonation reduced volume continuing intonation
- Underling text used to denote forms of emphasis
- () Single brackets used to indicate sections that were hard to hear or not hearable
- .hh hearable inhalation

latched talk

£ smiley voice

Fig. 1. Transcription symbols.

## 1.2. Findings

In the pre-consultation questionnaire just over a quarter of patients (79/281, 28%) reported 'going online' to seek information regarding the health issue about which they were consulting. In this paper we focus on data from the subset of 28 patients interviewed after the consultation (Table 1).

Patients referred to the internet to support either or both doctorability (statements justifying seeking medical assistance) and epistemic claims to knowledge (statements justifying knowledge) in all interviews and eight of the related consultations. Epistemic claims to knowledge were more common than work to establish the doctorability of problems (Table 2).

In the extracts doctors' contributions are marked as 'Doc', patients' as 'Pat' and the interviewer as 'Int'. For ease of reference interview respondents are referred to as patients. Extracts are marked with 'interview' or 'consultation' and for ease of recognition a calibri font is used for interview data and courier new for consultation data.

This paper compares reported uses of the internet by patients before consulting with video recordings of the consultation in question. Before examining matched examples, we consider patients' accounts from interviews of their use of the internet prior to consulting.

## 1.2.1. Patients' accounts of internet use

We observed that when patients referred to use of the internet they conveyed themselves as proactive but sensible – people who did not rush to the doctor but carefully examined their situations before seeking help for problems that were 'doctorable'. This is in line with previous work (Bowes et al., 2012; Stevenson et al., 2007) reporting that patients' accounts project an identity of responsible use of the internet to seek information before consulting the doctor and as such to only pursue medical care when absolutely necessary.

This is made clear in Extract 1 below. The patient suspects he has a hernia. He presents his primary epistemic rights to knowledge, in the form of his own knowledge and experience of hernias. This directs his internet search which leads to the 'unwelcome' realisation, based his

**Table 1** Characteristics of patients interviewed.

Identifier	Gender	Age	Condition
GP1_R116	M	56–65	Foot problem
GP1_R123	F	56-65	Urinary tract infection
GP1_R11	M	56-65	Suspected inner-ear tumour
GP1_R8	F	56-65	Blood in stools
GP1_R127	F	19-25	Throat feels bruised
GP2_R20	F	56-65	Blood test result
GP2_R54	M	46-55	Knee pain
GP3_R55	F	46-55	Shoulder pain
GP3_R73	M	56-65	Suspected hernia
GP3_R74	F	66-75	Knee replacement
GP3_R77	M	66-75	Hernia operation scar
GP3_R110	M	66-75	PSA test result
GP4_R100	F	36-55	Thyroid problem
GP4_R106	F	66-75	Hissing sound in one ear
GP6_R168	F	26-35	Pain in ear.
GP6_R175	F	26-35	Complications from deviated septum surgery
GP7_R202	M	0-18	Baby has oozing belly button
GP7_R192	F	66-75	Respiratory infection
GP7_R198	F	66-75	Urinary Tract Infection and Heart issues
GP8_R207	F	56-65	Pain behind knee
GP8_R216	M	0-18	Boy with spot on neck
GP9_R238	M	46-55	Discussion of recovery from throat cancer
GP9_R242	F	56-65	Review of overactive thyroid
GP9_R51	M	46-55	Lethargy, pain in chest
GP9_R253	M	56-65	Check up for diabetes
GP9_R244	M	66-75	Review of pain in head
GP10_R290	F	46-55	Lower back pain, numbness in tip of middle
			finger
GP10_R285	F	46–55	Mark on chest

**Table 2**Epistemic claims to knowledge and doctorability by patients in interviews and consultations.

	Interviews	Consultations
Epistemic claims	13	5
Doctorability	7	2
Both	8	1
Neither	0	6
Total	28	14

internet searches, that he needs to consult a doctor (his problem is doctorable).

## Extract 1 Interview

(	O1 Int: Okay. Now before you came in to see [Doc's name], erm, did you look at any
	02 sources of information? So magazines, television, internet, anything like that.
	03 Pat: Er, yeah. I looked, erm, I just Googled it and went through, erm, several
	courses I

<sup>04</sup> can't remember the websites

The patient presents himself as knowledgeable about his medical problem, citing suspicion he had a hernia when he first discovered a lump (line 06). He used the internet 'to confirm' his diagnosis (line 09)

and the need to seek treatment. He demonstrates the skills to check out his suspicions and confirm the next steps, conveying a dual identity as reluctant to attend while acknowledging the necessity (line 14). Later in the interview he discusses how he developed his searching skills in his work as a teacher, and how this enables him to be proactive in the consultation, something he considers to be important given the pressures under which doctors' work (Extract 2).

# Extract 2 Interview

01 Pat: So, I mean, because I was a teacher, just Googling and looking for information and

02 sifting out information, something I did all the time

03 (19 lines omitted discussing teaching)

 $04\,\text{Pat}$  . The benefit is that I come to the doctors and I have information about what it is

05 Int: Okay.

 $06\,\mathrm{Pat}$  : So if there is, so, erm, and, and having knowledge is important because vou

07 can ask certain questions. You can ask inform, you can ask the doctor. If the doctor

08 says, if the doctor, you can ask the doctor more about the, about what you've got

09 because you've got more information about what you've got.

10 Int: Mhm.

11 Pat: I'm not saying that you distrust doctors or anything like that. But in this day and

12 age with everybody under pressure, it's best to know what you're coming for. 13 Int: Mhm.

14 Pat: With, with an idea of what it is so that if they say it's, if they, if they're a little bit

15 vague then you can say, "Well, so what, what's the prognosis? What do you think 16 might happen next? What sort of treatment would you give me?" and so on and so

17 forth.

GP3\_R73

Here the patient lays claim to professional skills in effective internet searching. This builds on the previous account of his symptoms (extract 1) to suggest that a benefit of using the internet is the ability to make the doctor accountable for the diagnosis and allow the patient to know what questions to ask e.g. regarding treatment and prognosis. The use of the negative polarity statement 'I'm not saying that you distrust doctors or anything like that' (line 11) and claim in relation to the pressured conditions under which 'everyone' operates, emphasises an identity as someone who acts agentically not just to assess the need to consult but also to evaluate and critically assess what is said and done in the consultation. It also obliquely attends to the possibility that such patient work may function to challenge the traditional division raised by Landmark et al. (2015) between patients' epistemic rights to specific knowledge (about their bodies and direct experience of them) and doctors' epistemic rights to technical knowledge.

We now move to combine data from accounts in interviews of when and why people use the internet and analysis of instances the internet is invoked in associated consultations. We organise reflections on the 'work' of patients in raising the internet in interviews and consultations in relation to four concepts that are helpful in understanding medical interactions; (i) establishing doctorability (appropriateness of attending), (ii) establishing a diagnosis, (iii) establishing treatment and (iv) referral. This allows us to reflect on differences and similarities between patients' references to the internet in interviews and consultations and in so doing the consequences for supporting patient's experience of care.

#### 1.2.2. Establishing doctorability

Patient claims establishing doctorability are a recurrent feature in both the interview and consultation data. The appeal to doctorability in the interview data works to construct an identity as someone reasonable who does not rush to the doctor but rather considers what they can do

<sup>05 ((6</sup> lines omitted while patient details types of websites))

 $<sup>06\ \</sup>text{Pat:}\ I,\ I,\ I,\ I\ \text{suspected}$  that's what it was [hernia] right, you know, when, when I first

<sup>07</sup> discovered it.

<sup>08</sup> Int: Okay.

<sup>09</sup> Pat: So I was just tryin' a confirm my own diagnosis.

<sup>10</sup> Int: Right.

<sup>11</sup> Pat: And then see what the, erm, what might happen next.

<sup>12</sup> Int: Okay.

<sup>13 (...)</sup> 

<sup>14</sup> Pat: Er, I just thought, "Damn it, I'm gonna have to go see the doctor and get it started,"  $% \label{eq:continuous}$ 

GP3 R73

first. In contrast, in the consultation data, doctorability appears to be leveraged to justify care, particularly treatment.

In the following example the patient outlined a series of self-help measures, based on information from the internet, that she had tried to relieve her ear pain (not shown here). Extract 3 below contains two main ideas, (i) that she is only consulting because she has exhausted the self-help measures available to her and now needs medical advice, and (ii) the identity work associated with consulting.

# Extract 3 interview

```
01 Int: I seem to remember you sort of mentioned that you'd looked up and you'd tried,
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02 you know, the hot water bottle and all the different things.

03 Pat: Yeah.

04 Int: So you sort of told the doctor at the start, quite near the start of the consultation.

05 Pat: Yeah. Wanted her ((the doctor)) to know that I didn't just (0.2) I know it sounds

06 ridiculous but I didn't want her to think that I'd just turned up and not done 07 anything about it myself.

08 Int: Yeah.

09 Pat: I just want her to fix it. I tried to fix it myself and it didn't work

GP6\_R168

The patient starts by saying she wanted the doctor to know that she "didn't just" (line 05), and then cuts off, and pauses slightly before formulating the parenthetical insert to her turn; "I know it sounds ridiculous" (lines 5 and 6). Drawing on Mazeland's (2007) work on parenthetical sequences, this insert can be seen as a way of projecting an identity as someone who does not consult prematurely. This, and the repeat of "I didn't" following the parenthetical insert (line 06), works to establish a claim to doctorability. The extract signals the complexity of decisions to consult a doctor, with the internet invoked to support the construction of a morally accountable identity as someone who is consulting appropriately and also as a resource upon which claims for doctorability can be built.

In the consultation, the patient sought to establish the doctorability of her visit in the problem presentation phase of the consultation – a common place to justify help seeking. Specifically, following her characterisation of the problem as experienced as extreme (a searing pain) and the duration (four days), she invokes the internet as informing a succession of home remedies. In doing so she demonstrates the work she has already done in trying to solve her problem, while at the same time leveraging this to build a case for why she now needs medical treatment (Extract 4).

# Extract 4 consultation

01 Pat: I've got (0.2) searing pain in my e::ar? 02 [.hhh 1 = 03 Doc: [ °oh dear.°] 04 Pat: = and I've had it for.hhh (0.2) I think this is 05 day four now? (.)um (0.2)I've (0.1)looked it up 06 and I've tried to do (0.2) um (0.2) a hot 07 water bottle, (0.4) I took ibuprofen and 08 paracetamol. (0.3) > and I've decided they don't 09 work anymore.<.hhh and  $I^{^{\circ \circ}}$  (do) what else did 10 I do, ° I put menthol in a bowl? = 11 Doc: hmm hmm ((nodding)) 12 Pat: = and tried to breathe that in hot steam, 13 Doc: hhm hmm 14 Pat: and its just getting worse and worse and 15 worse..hh 16 Doc: have you ever had anything like this befo: re? 17 Pat: never °its so painful.° 18 Doc: no okay (poor thing.)

(continued on next column)

#### Extract 4 (continued)

19 Pat: it's been like four days [now ]

20 Doc: [veah.]

21 Pat: I'm really frustrated, hh the pain is like-

22 Doc: it is an awful pain. ()

23 Pat: its awful.hh h

24 Doc: yeah um so you said you looked it up wha what did

25 you think it might be::.

26 Pat: I assume its ern ear infection of some.((swallows))

27 Doc: yeah °okay°.

28 Pat: of some sort. Oh and (.) er this morning (0.6)

29 before i rang er um like bright fluorescent

30 yellow liquid came out my ear.(0.6)so h huh.

GP6 R168

In her description of her problem the patient provides an extreme case formulation (Pomeranz 1986) of "searing pain" (line 01). She skilfully links her action of looking for information with the action of supported self-management, rendering the looking as morally defensible (lines 05–06), and then produces a three part list (Jefferson 1990) of the measures she has tried in order to relieve the pain (hot water bottle, painkillers and steam inhalation) (line 06–12). She provides a repeated time reference, "four days", emphasising her prolonged discomfort, and describes her pain as getting "worse and worse and worse" (lines 14–15) with the repetition of "worse" serving to intensify the report of the symptoms and their increasing severity. In line 21 the patient moves from a description of her symptoms to referencing the impact on her life, what Bloch and Antaki (2019) refer to as the 'pivot point' enabling a move to the next phase of the consultation. At lines 24-25 the doctor refers back to the patient's report of use of the internet and seeks a 'candidate diagnosis' from the patient (Stivers 2002). The patient responds by saying that she "assumes" it is an ear infection "of some sort". This works to show awareness that there are different kinds of ear infection. This is important as diagnosis of a viral infection is unlikely to result in treatment, while diagnosis of a bacterial infection is (more) likely to result in a prescription for antibiotics. Leaving the closer specification of the particular type of ear infection to the doctor not only attends to the limits of her epistemic rights to knowledge about diagnoses (Heritage 2012), but also places the decision about treatment firmly back within the doctor's province. The patient then adds a new symptom, bright, fluorescent yellow liquid, coming out of her ear, anchoring this temporally, before she rang for an appointment (line 29), which shifts the focus back to the severity of her symptoms adding to the case for the doctorability of her concern. This is completed with a trail off of "so" (line 30) signalling completion of her symptom presentation and display of doctorability and establishing a need for action from the doctor.

The internet is used as the basis for action in relation to self-help before attending and to build a case for appropriate attendance, establishing her symptoms as doctorable. Despite a request for the patient to share her thoughts, based on her research, the patient leaves the identification of a solution to the doctor, resisting appearing to encroach into the doctor's epistemic domain of determining appropriate treatment. Although this is seemingly in line with what was reported in the interview, that she consulted for the doctor to 'fix' the problem, the patient skilfully builds a case for treatment, despite not explicitly voicing this in the consultation as an expectation.

## 1.2.3. Establishing a diagnosis

The next example (Extract 5) concerns a woman whose use of the internet was motivated by wanting to find out about asthma, a condition she "wasn't too sure" she had. In her interview she notes the pervasiveness and value of the internet, but also the volume of information on asthma and the difficultly of interpreting and filtering the information to identify that which is personally relevant. By invoking the internet she presents an identity of someone actively involved in seeking answers to her medical problems and concerns.

## Extract 5

01 Pat: Well yeah, we all look on the internet, don't we? ((interviewer laughs)) Frighten

02 ourselves as well. Yes, I got a lot from the internet,

03 ((51 lines omitted talking about other places she gets information from))

04 Pat: Yeah, 'cause, erm, there is so much about asthma and.

05 Int: Yeah.

06 Pat: Because I wasn't too sure I had it although I was, j-just to know how to, basic

07 treatment.

08 Int: Yeah.

09 Pat: Because I do have an inhaler, they gave me inhalers to start with.

10 Int: Hmmhmm.

 $11\,\mathrm{Pat}$ : But, erm, you know, some of it I don't think I really, really applied to me, and then

12 that's usual, there's loads of, erm, items and it doesn't always apply.

13 Int: No, hmmhmm.

14 Pat: I always think it's worth knowing, but sometimes I think you can know too much

15 and frighten yourself.

GP7 R192

The extract projects the normality of looking on the internet "everyone looks" (Line 01), alongside both the perils (frightening) and benefits (informative) (Line 02). The patient portrays herself as openminded insofar as she was unsure she had asthma but nonetheless sought to understand basic treatment. She speaks of the large volume of information available and the difficulty of filtering. Her phrasing (line 14) "I always think" (not just on this occasion) that "it's worth knowing" but sometimes "you can know too much" (not me but people generally) presents her thoughts in relation to using the internet as both general and normal.

In the consultation the patient presents with a possible chest infection for which she suggests she might need antibiotics. She describes her chest problem as having started with an asthma attack, although she had never had an attack before (not shown here). She then moves to indicate that she doesn't know enough about asthma, despite looking on the internet, while also reflecting on the amount of information available. The doctor looks at the patient's notes and discusses the history of this medical problem, after which the patient returns to her lack of knowledge about asthma, this time with a direct reference to an alternative diagnosis of bronchiectasis, indexing this as an issue of confusion. The doctor agrees to review her notes to provide clarification about the diagnosis. In this way the internet is invoked to lobby for the doctor's engagement and expertise (Extract 6).

# Extract 6 consultation

01 Pat: Yeah I don't know enough about this asthma. = I feel a bit

02 (.) at sea with that but nevermin:d, I go on the internet

03 an' read up about it [but.hh[h there's lots t' (0.3) =

04 Doc: [((turn to screen))

05 [.hHH mcht hhhh

06 Pat: = sort've take in about asthma,

07 (0.6)

08 Doc: Mcht hh there i:s an' i- if I just go back < to the last

09 time th't you were seen> in clinic just to remind myself,

10 ((1m 55 s omitted for check of patient record and

11 previous diagnosis))

12 Pat: Well it is because I (0.5) >I I thought < am I are we

13 working on asthma (.) or am I working on bronchiectasis

14 y'see I(0.8) I just get totally confused an' I feel I don't

15 (0.3) know enough about (0.4) asthma,.hh (.) um: than I

16 should. I go on the internet (°but that's°) ([ ])

17 Doc: [N}o:. = .HH

18 Do you know what I think we should do, coz I don't want to

19 jump to saying one thing or the other. = I need to have a

20 proper look through your notes.

GP7\_R192

Critical for us is that the patient produces a mild complaint about how much there is to take in about asthma on the internet (lines 03–06) which presupposes the relevance of asthma knowledge to her. However, it is important to note that following the patient's assertion that "there's lots t' (0.3) sort've take in about asthma" (line 06), the doctor competes epistemically by stating "there i:s" (line 08) (see Stivers 2005b on modified repeats). Yet, the patient does not let this stand, contesting ownership over the statement by returning to this concern after the doctor has looked at the medical record with a direct question about her diagnosis and an alternative diagnosis (bronchiectasis) (line 13). The patient can be seen to proactively seek clarification about her diagnosis in a context where asthma had been somewhat pre-supposed. The doctor responds by suggesting a need to review the patient's medical notes (line 20), pulling back from further discussion of the patient's medical problem.

The patient works to establish the doctorability, or appropriateness, of concerns about diagnosis until the doctor agrees to review the medical evidence. Reference to the internet in both the interview and consultation data means the patient is able to position her challenge as grounded in her confusion in relation to what she had read about the diagnosis and how it fits with her medical problems, avoiding an explicit challenge on the doctor's epidemic privilege in relation to diagnosis.

#### 1.2.4. Establishing treatment

Here, the doctor and patient appear to agree about the diagnosis, however the basis for treatment both on the internet and recommended by the doctor proves more problematic. In the interview the patient reports pain in their toe, which they suspect to be gout. Having confirmed their suspicions by looking on the 'NHS Website' they booked an appointment. They report that the website contained details of the foods associated with gout and that this did not correspond with the foods they would normally eat (an issue which is then taken up in the consultation). Here we present the more general account the patient provides of the importance of having looked on the internet before a consultation to prepare for the discussion, enhance understanding and interpret the information provided by the doctor in time-limited consultations (Extract 7).

# Extract 7 interview

01 Pat: Yeah. I, it's, I, I've got a little bit of an understanding, but it's, of stuff anyway. Erm.

02 and it just helps out, so, because it doesn't matter. When you're in the doctor,

 $03\ you're$  only in there  $10\ or\ 15\ min.$ 

04 Int: Right.

05 Pat: And he could be saying an awful lot to you. And sometimes especially if it's

 $06\ something\ serious,\ I\ guess,\ you're\ not\ gonna\ take\ it\ all\ in.\ And\ so.$ 

07 Int: Yeah

 $08\ \mathrm{Pat}$ : If you've, if I've got an idea beforehand what he's gonna be saying, at least then the

09 bits I remember from the web, if he confirms them then all I've gotta do is

10 remember the bits that he tells me that I didn't see on the web.

11 Int: ((interviewer laughs)) Narrows it down.

 $12\ \text{Pat:}$  Yeah, yeah, so that, so that helps, er, that helps to kind of build up the information,

13 so yeah.

GP1\_R116

The account starts with the patient positioning himself as somewhat knowledgeable about medical "stuff" (line 01). Although he minimises his understanding as "a little bit", he nonetheless paints a picture of himself as moderately informed through use of the internet and with knowledge that can then be readily *augmented* by what the doctor tells him

In the consultation the patient is diagnosed with gout. Following the

diagnosis, the doctor and patient transition to the treatment phase. Up to this point the patient has not mentioned the internet, however when the doctor raises the need to discuss "lifestyle measures" and prescribe anti-inflammatory tablets, the patient introduces his research and raises a mismatch between his lifestyle and the behaviours typically associated with gout (Extract 8).

## Extract 8 consultation

```
01 Doc: ((Reading a medical handbook))
  02 Mcht.hh So what we do is we give you anti-inflammatory
  03 tablets,(0.8)they usually get rid of it quite
  04 satisfactorily.
  05 (0.6)
  06 Doc:.hhh We talked t'you about l:ifestyle measures, (.) an'
  07 then if it keeps happening there's another
  08 [tablet we can put you on t' (.) try an' prevent it,]
  09 [ ((g a z e to p a t i e n t)) ]
  10 Doc: [((Continues reading medical handbook//computer work))]
  11 [ (18.5)//(15.3) ]
  12 Pat:.hhh Ironically I had a quick look on the web and um:
  13 (1.5) uhh there was a list've (.) things that can (0.2)
  14 the f:oods that're more likely to bring it on.
  15 (0.2)
  16 Doc: Good,
  17 Pat: And one've 'em was oily f:ish > an' I< thought, e- evr- if
  18 everything £else in the world you're supposed to
  19 [e a t o i l v f i s h.h h] and the irony is I =
  20 Doc: [ ((stretches out hand, nods)) ]
  21 [ °h u h h yeah°]
  22 Pat: =(.) disli(h)ke i(h)t s:[huh a: lot've the things =
  23 Doc: [huh huh huh ((wheezy))
  24 Pat: = that're s'pposed to bring it on I don't like eating
  25 anyway.£ = .hh But uh (1.5) mcht I s'ppose I've been uh:: a
  26 tad overweight (.) all through my life an' I s'ppose it
  27 i'st- (.) it's one've those things th't-.hh > if you<
  28 (argue) like that, I mean I'm fairly active 'n do stuff
  29 b't-.hhh (as if you're) if y- if you're long time uh (.)
  30 y'know over yer the weight yer should be may[be then: =
  31 Doc: [°Yeh°
  32 Pat: =(.) it just brings it on.
  GP1 R116
```

The patient does not clearly resist a diagnosis of gout (which is how we might understand this if brought up immediately after the diagnosis), rather he presents a potential challenge to the doctor's treatment recommendation. The recommendation is offered as a generic solution: "what we do is we give you anti-inflammatory tablets," (lines 02–03). At this point, there is an opportunity for the patient to accept the treatment recommendation or at the very least acknowledge it (Stivers 2005a). However, this is not forthcoming, and after nearly a second, the doctor then re-completes his turn citing the effectiveness of anti-inflammatory tablets (lines 03–04). Here is another opportunity for the patient to accept the treatment, but again this is not taken (line 05).

After another delay, the doctor initiates another line of treatment – "lifestyle measures". This is also not readily embraced, made visible by the micropause (line 06). Failing yet again to secure acceptance, the doctor then offers a contingency plan (Mangione-Smith et al., 2001) in the form of another tablet (line 08) and shifts their gaze to the patient (line 09).

Patient acceptance is still absent. It is important to note that this patient has passed on four opportunities to accept the recommendation, but also that acceptance is due at the end of a recommendation. Its absence makes this hearable, to both the doctor and us as analysts, as passive resistance.

There is an extended silence (33.8 s) while the doctor looks up information; the silence is broken when the patient launches into an account of what he knows about lifestyle measures, based on a "quick look on the web" (line 12). The talk is initiated with an audible inbreath and the word "ironically" suggesting talk that may not align or affiliate with

the previous talk, providing further evidence of his 'resistance'. The patient goes on to detail how the lifestyle factors, specifically foods, listed on the internet as associated with gout do not fit with his lifestyle. The patient presents himself as someone who would be unlikely to have gout. Although he acknowledges he 'supposes' he's "a tad overweight" (line 26), the hedging in relation to repeated use of the term 'suppose', the minimisation of the extent of his excess weight with 'a tad' and his immediate move to indicate that he is active (line 28) cohere to problematise this explanation.

The extract from the consultation, in line with the patient's assertion in interview about the need to 'build up' an understanding based on information from both the internet and the doctor, illustrates how information from the internet may be leveraged by patients to raise concerns about proposals inside the consulting room, here relating to the aetiology of gout. Although the patient appears to accept the diagnosis, he works to resist the identity of having gout because of his lifestyle. He uses information from the internet to subtly contest both the treatment and the basis for the diagnosis, presenting the 'puzzle' of why he had developed gout and clearly expressing the limitations of lifestyle changes in relation to both prevention and treatment.

The doctorability of the patient's problem is not in question, however the patient's resistance of the basis for treatment, according to what he has read on the internet, presents a fundamental challenge to the epistemic authority of the doctor, albeit positioned as a 'puzzle'. Although the patient in his interview presented the internet as a resource used to augment what was said in consultations, here we see how information from the internet may also be used by patients to seek clarification.

#### 1.2.5. Referral

This example concerns a woman with knee pain who had previously been offered a knee replacement but declined because she didn't think her pain warranted a replacement joint. However, having become increasingly debilitated she sought to revisit this option. In the interview she reports having researched on the internet to identify the best consultant and requesting a referral to see him (Extract 9).

#### Extract 9

GP3 R74

```
ask to be
02 able to see ((consultant's name)).
03 Int: Right.
04 Pat: People at the ((hospital 1)) because I've been reading up about them, 'cause I go
05 online, typey, typey, typey, looking for all this and ((laughs)) having been a researcher,
06 and worked in research.
07 Int: Yeah, of course, yeah.
08 Pat: You know, I go online and research everything.
```

01 Pat: .... Erm, and then she said "We'll arrange that you can see a consultant." I did

The patient states that once an offer of a referral had been made, she requested a named consultant (line 02) at a particular hospital, supporting this with reference to the internet. Although she initially presents her internet searching in a light-hearted, jokey way, using the repeated phrase "typey, typey, typey" (line 05), accompanied by an audible representation of typing, and characterises her use of the internet as 'looking', she seamlessly transitions to present herself as having been a researcher and as someone who goes online and researches "everything".

In the consultation the patient openly lobbies for a referral (not shown). As soon as the doctor indicates she will provide a referral the patient launches an inquiry – conditioning her acceptance of the referral on this (Extract 10).

#### Extract 10

01 Doc: so lets do that referral (0.4) u::m en get you back in 02 to seeing the (.) (specialist) doctors (0.6).hhh 03 u:::m, we:::[::,]
04 Pat: [wh] lich o:nes, would I be able to go to 05 ((hospital name)), because (0.4) I've I've (.) I've I've 06 heard excellent reports about ((hospital name)) > and 07 and < I've also researched them online and.
09 Doc: mm[:::,]
10 Pat: [they] are the top guys and because I'm (.) rea:lly 11 nervous having had other operations that have gone 12 "wrong".
GP3\_R74

The request for a referral to a specific hospital is only produced by the patient once the offer of a referral had been made by the doctor. The patient overlaps the offer with a query as to which team, and then initiates repair, requesting referral to a named hospital (lines 04–05). The patient accounts for her request in terms of what she has "heard" and what she has "researched" (lines 06–07). She completes by orienting to previous negative experiences, in this way minimising the chance of being categorised as demanding and instead as understandably concerned and cautious (lines 11–12). All of this is hearable as lobbying for a referral to a specific hospital as a pre-condition for her acceptance of the referral.

The request in the consultation is for a named hospital, not a named consultant (as reported in the interview data). We can speculate that naming of a hospital as opposed to a consultant was better fitted to the prior talk by the doctor in the consultation which was in relation to a medical specialism as opposed to a specified medical team. Moreover, in the consultation the internet was invoked alongside what she had 'heard' as well as with reference to previously negative medical experiences, making reference to the internet hearable as less strongly asserted in the consultation than in the interview.

The patient is clear in both the interview and consultation about the need for a referral and as such the doctorability of her medical visit. Making a request for a particular hospital or team is not in itself a challenge to the authority of the doctor, particularly as in the UK there is the possibly of choice in accessing secondary care, however the positioning of the request in overlap following the doctor's offer of a referral could be seen as a possible challenge to the doctor's rights to specify the best location for further treatment.

#### 2. Discussion

We know from interview-based research that people are reluctant to mention that they have used the internet when they consult their doctor, due to previous negative experiences (Bowes et al., 2012; Stevenson et al., 2007). We examined patients' accounts of internet use and compared this with interactional data from the associated consultation.

We used a conversation analytic approach to systematically inspect accounts from interviews concerning use of the internet alongside analysis of the ways in which patients produced and presented their use of the internet in their consultations. This approach resembles microethnography as described by Timmermans and Stivers (2017, 2016). We used the concepts of doctorability and epistemic authority to reflect on patient accounts of their use of the internet outside of a consultation and to consider how this compared to the discussion of the internet in specific consultations.

Analysis of the interviews indicated that, in line with previous work in primary care (Bowes et al., 2012; Stevenson et al., 2007) and elsewhere (Pope et al., 2019), patients' accounts project an identity of responsible use of the internet to seek information before consulting the doctor and as such to only pursue medical care when absolutely necessary and for problems that were 'doctorable'. In addition, the internet was also presented as creating:

a felt imperative to be (or to present oneself as) an expert and critical patient, able to question one's doctors and nurses and locate effective treatments for oneself (Ziebland 2004:1792)

Accounts from interviews outlined how access to information from the internet informed and supported decisions to consult. In line with previous work (Stevenson et al., 2007), the internet was presented as a source of information to support, rather than challenge, the epistemic position of the doctor.

Data from interviews and consultations were used together to consider four key areas of concern in medical interactions namely (i) establishing doctorability (appropriateness of attending), (ii) establishing a diagnosis, (iii) establishing treatment and (iv) referral.

We saw how a case for treatment was skilfully built by detailing self-help measures from the internet that had failed to alleviate the symptoms, clearly asserting the doctorability of the problem, with a desire for treatment expressed in the interview but not in the consultation. Avoidance of providing a candidate diagnosis, which might be treatment implicative, left the identification of a solution to the doctor thus avoiding appearing to encroach into the doctor's epistemic domain of determining appropriate treatment.

When discussing diagnosis, reference to the internet in both the interview and consultation data allowed the patient to position a challenge to an assumed diagnosis as grounded in confusion in relation to what she had read about the diagnosis and the fit with symptoms. This made it possible to present this apparent challenge as appropriate. The nature of the presentation avoided an explicit challenge to the doctor's epistemic privilege in relation to diagnosis.

We saw how repeated failures to accept a proposed treatment was based on a mismatch between how a medical problem was described on the internet and how the patient saw himself in relation to the diagnosis. The characterisation of this as a 'puzzle' had the effect of reducing the potential challenge to the doctor's epistemic authority in relation to treatment. Interestingly the interview suggested that the internet was used as a supplement to time-limited consultations rather than to reveal potential mismatches in understanding between doctor and patient.

Finally, in considering the request for a referral to a specific provider, reference to the internet was used to assert the appropriateness in both the interview and the consultation. However, the actual positioning of the request in the consultation (in overlap with the doctor's talk) could potentially be seen to work as a challenge to the doctor's epistemic authority in determining the next steps.

We have demonstrated the ways in which patients present themselves in both interviews and consultations as conscious of the 'double-bind' (Bloor and Horobin 1975). Analysis of interview data provides an understanding of how patients present themselves as seeking information from the internet to support decisions to consult (doctorability) and to inform themselves about diagnosis and treatment options in primary care and beyond. Analysis of consultation data demonstrates that although there are obvious fundamental asymmetries at play between doctors and their patients (Peräkylä 2002), patients skilfully use mention of, or information from, the internet to invite specific courses of action from their doctors. They do this without disrupting the flow and sequential organisation of the consultation and by using language that clearly respects medical knowledge and generally does not openly challenge the epistemic authority of the doctor.

Access to medical care is under additional pressure in current times given the global pandemic, which is likely to further increase use of the internet for health-related queries and care. Doctors are likely to remain unaware of the extent of patients' internet searching unless they ask (without judgement) and pro-actively invite patients to talk about what they found and what they would like from the consultation. Unless doctors do this patients are likely to continue to weave in pertinent findings from internet searches taking care to work within, albeit with occasional delicate pushing against, existing asymmetries so as not to disrupt doctors' primary epistemic rights to knowledge in relation to the

diagnosis and treatment of medical conditions.

#### **CRediT** author statement

Fiona A. Stevenson: Conceptualisation, Methodology, Formal analysis, Writing – original draft, Supervision, Project administration, Funding acquisition, Maureen Seguin: Investigation, Writing – review & editing, Geraldine Leydon-Hudson: Conceptualisation, Writing – review & editing, Funding acquisition, Rebecca Barnes: Conceptualisation, Writing – review & editing, Funding acquisition, Sue Ziebland: Conceptualisation, Writing – review & editing, Funding acquisition, Catherine Pope: Conceptualisation, Writing – review & editing, Funding acquisition, Elizabeth Murray: Conceptualisation, Writing – review & editing, Funding acquisition, Writing – review & editing, Funding acquisition, Writing – review & editing, Funding acquisition.

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