

# Online Health Communities and the Patient-doctor Relationship: An Institutional Logics Perspective

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## Abstract

Taking an institutional logics perspective, this study investigates how “internet-informed” patients manage tensions between the logic of personal choice and the logic of medical professionalism as they navigate treatment decisions and the patient-doctor relationship. Based on 44 semi-structured interviews with members of an online health community for people with diabetes, this study finds that patients exercise a great deal of agency in evaluating healthcare options not only by activating the logic of personal choice but also by appropriating the logic of medical professionalism. Furthermore, patients are strategic in deciding what community advice to share with their doctor or nurse depending on the healthcare professionals’ reaction to the logic of personal choice. In contrast to many previous studies that emphasise patient consumerism fuelled by information on the Internet, this study provides a more nuanced picture of patient-doctor relationship engendered by patients’ participation in online health communities.

**Keywords:** online health communities, patient-doctor relationship, institutional logics, diabetes

## **Introduction**

Members of online health communities (OHCs) can collectively produce health knowledge by synthesising different forms of evidence including patients' experience and medical research (Bellander and Landqvist, 2020). Knowledge from these communities empowers patients by giving them greater control over their condition, choice over treatment options, and autonomy in decision making (Willis and Royne, 2016). This logic of personal choice is linked to patient consumerism whereby patients make decisions based on personal judgement and health information resources publicly available on the Internet (Barker, 2008; Broom, 2005). Patients who subscribe to this logic are not opposed to mainstream medicine but view it as one of a series of options they choose from depending on their personal circumstances and need (Lemire et al., 2008).

While healthcare professionals welcome informed and empowered patients who are actively engaged in health self-management (Newton et al., 2011), Internet-informed patients have added a layer of complexity and uncertainty to clinical consultations. Some healthcare professionals may resist patients' choice of alternative solutions found on the Internet when they view it as a threat to their authority. Others may be willing to support or even encourage patients in pursuing these alternative solutions if they perceive them to be medically sound and are consulted about them (Caiata-Zufferey and Schulz, 2012). By contrast, they are less willing to discuss solutions which, in their view, fall outside recognised treatment protocols, are not scientifically proven, and can potentially put patient safety at risk (Stivers and Timmermans, 2020). Therefore, healthcare professionals are sensitive about the medical legitimacy of online health information, and the extent to which patients relying on this information encroaches with their professional authority and duty of care. When treatment options that patients have found online are at odds with medical legitimacy or professional responsibility (Lemire et al.,

2008), a tension between the logics of medical professionalism and personal choice is likely to arise, which could put a strain on the patient-doctor relationship.

In this paper we investigate how patients manage tensions between these two logics and what consequences this has for the patient-doctor relationship and patients' decision making about treatment. Tensions between the logic of personal choice and the logic of medical professionalism emerge from patients' own agency and interactions with healthcare professionals and OHCs. The individual patient has the ability to evaluate treatment options and act upon them (Koenig, 2011), potentially generating tensions with healthcare professionals, who need to maintain their authority but, at the same time, be open to alternative knowledge and practices patients may have found on the Internet. OHCs may augment these tensions by appraising and shaping patient experience and actions through online discussions. Against this background, this study aims to address the following research question: *How do patients manage tensions between the logics of personal choice and medical professionalism arising from their interactions with OHCs and their healthcare professionals?*

How patients deal with these tensions affects the co-constructed relationship with their healthcare professionals, and ultimately, their treatment decisions and outcome. Evidence from observations of consultations is insufficient to address this question since patients rarely reveal their Internet sources when they discuss options with their doctor (Stivers and Timmermans, 2020). In this paper we interview patients who are active members of an OHC for diabetes about their experience with tensions between the two logics, aiming to provide new evidence of how the democratisation of knowledge through OHCs and the Internet affect the patient-doctor relationship and patient agency in making treatment decisions.

The remainder of this paper is structured as follows. We first review the literature on the patient-doctor relationship in the digital era. This is followed by a definition of institutional logics and a classification of the logics of personal choice and medical professionalism. We

then explain our empirical research methods before presenting findings from the case study of an OHC for people with diabetes. We conclude the paper with a discussion of implications and limitations.

## **Patient-Doctor Relationship in the Digital Era**

There is no doubt that the Internet and digital technologies have radically altered the balance of power between physician and patient and accelerated the shift towards more patient-centred healthcare (Johansson et al., 2021; Lemire et al., 2008; Mano, 2014; van Uden-Kraan et al., 2009). For example, search engines facilitate easy access to medical knowledge previously available only to healthcare professionals (Eysenbach and Köhler, 2002) and various social media provide spaces for experiential knowledge sharing and peer support among patients themselves (Sendra et al., 2019; Smailhodzic et al., 2016). Much ink has been spilled on this “democratisation of healthcare” which improves patient self-care, enhances patients’ subjective wellbeing, and leads to better clinical outcomes (Coleman and Newton, 2005; Lin and Kishore, 2021; Merolli et al., 2013; Santoro et al., 2015).

The shift towards patient-centred care also has profound impact on the patient-doctor relationship (McMullan, 2006; Smailhodzic et al., 2016; Tan and Goonawardene, 2017). The traditional patient-doctor relationship built on a paternalistic assumption that healthcare professionals know what is best for patients (Spencer, 2018) has largely been abandoned since 1980s (Kilbride and Joffe, 2018). Nowadays, the patient-doctor relationship is increasingly “egalitarian” (Stivers and Timmermans, 2020) and patients are becoming more involved in medical decision making (Bussey and Sillence, 2019).

Overall, the literature has presented mixed evidence on the impact of internet-fuelled patient empowerment on the patient-doctor relationship (Luo et al., 2022). Broadly speaking, the literature has focused on two aspects of the problem: 1) how patients act upon the information

they obtain online in their clinical encounters with healthcare professionals, and 2) how healthcare professionals react in such encounters.

Research has shown mixed reactions as well as scepticism from healthcare professionals regarding patients' use of Internet information and patient-oriented OHCs (Benetoli et al., 2018). In Ahmad et al.'s (2006) focus-group study, physicians generally considered Internet health information as problematic because it caused patient confusion, distress, and potentially harmful self-treatment. More evidently, these time-pressed physicians felt extra burden in consultations when discussing about pieces of information patients found online or dealing with "Internet-informed" patients who challenged their expertise. Stivers and Timmermans (2020) worry that, as the patient-doctor relationship morphs into a consumer-provider relationship, doctors are not only losing ground in the deontic domain ("I cannot dictate my patient's course of action") but also in the epistemic domain ("I have to defend my expertise against competing forms of knowledge"), which could lead to widespread medication scepticism found in Internet support groups. Other studies highlight the positive impact of Internet use on patient empowerment, in terms of enhanced sense of control over the disease and decision making (Broom, 2005), and find that Internet health information seeking can help improve the patient-doctor relationship if physicians are receptive to discussing the internet usage with patients (e.g., Rupert et al., 2014; Tan and Goonawardene, 2017). On the other hand, if patients experience resistance or confrontation from their physicians when attempting to discuss online information, it has adverse effects on the patient-doctor relationship (Tan and Goonawardene, 2017) and, consequently, undermine patient empowerment (Broom, 2005). Similarly, in a literature review of social media use by patients, Smailhodzic et al. (2016) summarised both positive and negative effects of social media use by patients on the relationship between patients and healthcare professionals: social media help create a more equal communication between the patient and their doctor, but at the same time can result in

“suboptimal interaction” between the two parties or even lead to increased switching of doctors. If a patient experiences a negative reaction from their doctor when an OHC is mentioned, it will drive the patient back to the OHC to vent their dissatisfaction about the medical encounter (Benetoli et al., 2018; Petrič et al., 2017).

While patients find doctors’ resistance to Internet information and their treatment preferences disempowering, patients’ use of the Internet and OHCs does not necessarily undermine the patient-doctor relationship (Timmermans, 2020). Moreover, there is evidence in the literature suggesting that “Internet-informed” patients make effort to manage their relationship with healthcare professionals in the medical encounters. Patients are cautious in presenting ideas from their online research in the consultation in fear of appearing to challenge the doctor’s authority and provoking a negative reaction from doctors (Stevenson et al., 2021). Patients choose to discuss the health information they obtain online only when they believe that the doctors are willing to listen (Luo et al., 2022). Vale and Good (2020) contend that patients experience trust in clinicians when they perceive clinicians transcending the formal bounds of medical professionalism.

To summarise, the literature draws a complicated picture of how patients’ consumption of OHC content and Internet health information influences the patient-doctor relationship. On the one hand, patients feel empowered when their doctors are willing to discuss Internet health information, but they also face scepticism and resistance from healthcare professionals and are therefore reluctant to discuss the information they have found online with their doctor. On the other hand, it appears that patients are aware of, and attempt to prevent or manage potential conflict from discussions of online health information with their doctor. We argue that how patients choose to approach discussions of OHC content and Internet health information with their doctor depends on how they manage tensions between their own logic of personal choice

(reinforced by interactions in OHCs) and healthcare professionals' logic of medical professionalism.

## **Medical Professionalism and the Logic of Personal Choice**

Institutional logics are cultural resources, material practices, norms, values, and beliefs, through which individuals and organizations organize their daily activities, lives, and experiences (Thornton and Ocasio, 2008). The theory of institutional logics has mostly been used in organization studies to investigate the behaviour of organisations and individuals (Lounsbury, 2002; Marquis and Lounsbury, 2007) within an organisational field (DiMaggio and Powell, 1983). In healthcare, an organisational field is made of actors that define the production and consumption of healthcare products and services, such as health service providers, regulatory and medical professional bodies, healthcare practitioners as well as patients or consumers (Bernardi and Exworthy, 2020). External influences and innovations may carry new logics that challenge the dominant logic of an organisational field. How actors manage conflict between logics, i.e., by resisting the new logics or by negotiating competing logics, may affect the extent of change within an organisational field (Marquis and Lounsbury, 2007; Pache and Santos, 2010). In this respect, various studies have shown that actors can straddle between competing logics and selectively appropriate more than one logic to define a particular course of action (Bernardi and Exworthy, 2020; Boonstra et al., 2017).

Relevant for our study are the tensions between the logic of medical professionalism and the logic of personal choice. While the logic of medical professionalism can be considered an historical logic governing healthcare professionals' action and relationships with patients (Freidson, 1985), the logic of personal choice is a more recent logic that penetrated the healthcare organisational field on the wave of patient consumerism brought about by the Internet (Lemire et al., 2008; Vinson, 2016). The logic of medical professionalism emphasises

healthcare professionals' autonomy and authority in recommending the most clinical effective treatment for a patient (Harris and Holt, 2013; Kitchener and Exworthy, 2008; Reay and Hinings, 2009). Under this logic, healthcare professionals' practice is mandated and sanctioned by the entire healthcare system from medical schools to clinics to the medical scientific community (Currie and Guah, 2007) and is governed by clinical guidelines and protocols (Bernardi and Exworthy, 2020). Professional authority and reputation are essential to gain patients' trust and respect, which are the cornerstones of a functional patient-doctor relationship (Kitchener and Exworthy, 2008).

While the logic of medical professionalism has been widely studied, particularly in the context of health sector reforms and innovation (Currie and Guah, 2007; Reay and Hinings, 2005; van den Broek et al., 2014), references to the logic of personal choice in healthcare are scattered across literatures on the consumption of health information online (e.g., Lemire et al., 2008) and patient-centred care (e.g., Shaw et al., 2017). The logic of personal choice has its roots in consumerism (Latimer et al., 2017; Lemire et al., 2008) and the rise of patient expertise fuelled by Internet access to health information (Fox et al., 2005). In addition, this logic has made its way into healthcare systems through recent healthcare policies promoting patient-centred care and patient empowerment (Klecun, 2015), particularly through the adoption of information technologies (e.g. telehealth, self-tracking devices) that give patients more control over their own health (Bernardi and Exworthy, 2020; Petrakaki et al., 2018). These policies, together with the adoption of self-care technologies, have inevitably augmented tensions between the logic of personal choice and the logic of medical professionalism governing medical practice and the patient-doctor relationship.

Under the logic of personal choice, patients take responsibility of their choices and have more control over their treatment decisions (Shaw et al., 2017), including whether to choose alternative or complementary treatments (Broom and Tovey, 2008). It is not unusual for

patients who subscribe to this logic to view healthcare professionals' advice to be paternalistic (Kitson et al., 2013), thus creating tensions with the logic of medical professionalism, which regards healthcare professionals as the sole authority in the provision of care. Patients' access to a wider range of treatment choices through OHC may fuel tensions between the logic of personal choice and medical professionalism (Stivers and Timmermans, 2020).

According to Thornton et al. (2012), institutional logics are composed of categories, which present individuals and organisations with an understanding of sources of legitimacy, authority, identity, norms, and attention that influence their action. We use these categories to compare the two logics of medical professionalism and personal choice (Table 1).

<b>Categories</b>	<b>Logic of medical professionalism</b>	<b>Logic of personal choice</b>
Sources of legitimacy	Education, medical knowledge, and expertise (Currie & Guah, 2007)	Patients' experience of living with an illness (Kitson et al., 2013)
Sources of authority	Professional authority, patients should follow medical advice (Reay & Hinings, 2009)	Patients are responsible for their own treatment choices and decisions (Kitson et al., 2013; Lemire et al., 2008)
Sources of identity	Association with professional bodies (McDonald et al., 2009)	Patients' autonomy (Kitson et al., 2013)
Basis of norms	Clinical guidelines and protocols (Bernardi & Exworthy, 2020)	Patients' needs, preferences, and experience (Klecun, 2015)
Basis of attention	Focus is on doctor-patient relationship, professional autonomy in treatment recommendations (Kitchener & Exworthy, 2008)	Focus is on patients' right to make autonomous health decisions (Shaw, 2016)

**Table 1. Comparison between the logic of medical professionalism and the logic of personal choice**

## **Research Methods**

This paper is based on a qualitative study of a large, UK-based OHC for people with diabetes (PwD). The OHC offers an open platform where PwD provide peer support and exchange tips

and knowledge on how to live with diabetes. Diabetes is a chronic condition that is managed through medication, diet, and exercise. In contradiction with official clinical advice in England, which recommends PwD a diet high in carbs, the OHC advocates a low-carb diet to reduce oral medications for people with type 2 diabetes (T2D) and the amount of insulin for type 1 diabetes (T1D) or insulin-dependent T2D. This contradictory advice makes diabetes an interesting case to study the tensions between the logics of medical professionalism and personal choice.

The research was approved by the authors’ institutional research ethics board and supported by the OHC company’s senior executives. Participants were recruited both through an advert posted on the forum and through an online survey (reported in Anonymous (2020)) of forum members, which asked participants to leave their contact if they wished to take part in a follow-up interview. The first author of this paper conducted 44 semi-structured interviews with members of the community between June 2017 and January 2019, each lasting 50 minutes on average. Recruitment stopped when a point of data saturation about recurrent themes (e.g. “bad/good relationship with doctor/nurse”) was achieved. No specific criteria were used in the sampling of participants, whose details are summarized in Table 2.

<b>Characteristics</b>	<b>Number of participants</b>
<b>Sex</b>	
Male	23
Female	21
<b>Type of diabetes</b>	
Type 1	20
Type 2	24
<b>Membership duration</b>	
Less than 1 year	2
1-2 years	19
3-5 years	17
6-10 years	4
More than 10 years	2
<b>Total</b>	<b>44</b>

**Table 2. Interviewee Demographics**

During the interviews, participants were asked to comment about how they evaluated and contributed content in the community as well as how their participation in the OHC affected their wellbeing, empowerment, and relationship with their doctor or nurse (see interview schedule in the appendix A1). Interviews were conducted either on the phone or through Skype, digitally recorded with participants' permission, transcribed, and anonymised.

The first author and a research assistant independently coded the interviews and met to solve any disagreement. An inductive methodology was followed whereby themes identified were grounded in the data (Glaser and Strauss, 1967; Sarker et al., 2000; Urquhart et al., 2010). Initial themes identified through open coding include the role of the OHC in influencing patients' decision-making and the patient-doctor relationship, institutional logics of personal choice and medical professionalism, the role of patients in mediating between these two logics, and healthcare professionals' response to patients' requests during consultations. These themes were then grouped under a more comprehensive scheme of recurring categories through axial or second-order coding which, subsequently were aggregated into overarching categories (Gioia et al., 2012) (see examples of coding in the appendix A2). Participants held different views about conventional medical advice on diabetes, as well as the relationship with and support from their healthcare professionals (see appendix A3). These views were contingent to specific circumstances and underpinned participants' strategies in mediating between the OHC's and healthcare professional advice.

## **Findings**

### **OHC expands treatment choices**

Participants generally felt that healthcare professionals were offering them little choice on how to manage diabetes on their own. In their view, medical professionalism was conservative and paternalistic. Some participants with T2D said that healthcare professional advice was mainly

focused on treating symptoms (e.g. the rise in blood glucose) with the prescription of medication, rather than preventing symptoms with diet. In their view, healthcare professionals' message that T2D is a progressive disease that requires more and more medication was "void of hope". While participants with T1D had no choice but to manage diabetes with insulin, they also found that the health service was not giving them much support on how to improve their self-management and be more consistent in their insulin management and control of diabetes with diet. Overall, there was a widespread view that healthcare professional advice was out-of-date and not open to emergent treatments that could help patients take control of their own health and be more independent through diet, testing (particularly for people with T2D), better glucose monitoring, and insulin management (particularly for people with T1D or T2D on insulin). Therefore, participants looked for further information on the Internet and the forum to try and help themselves in managing the condition:

*"I was struggling to lose weight with the diabetes, [...] and I was [...] wanting to try and find out how other people were doing it, [...] the dietician was not overly helpful [...] and just [...] told me to eat less, and [...] I'd already been on a very restricted diet and it hadn't made any difference" (P45, T2D).*

By contrast, several participants found that the OHC's advice helped them be more proactive in taking control of their condition. The online community was offering advice on diet for both T1D and T2D and diabetes technologies (e.g. Continuous Glucose Monitoring (CGM) and insulin pumps) as well as peer support about the day-to-day living with diabetes. The community's narratives of success and bulk of experiential evidence, particularly in relation to treatments that would not be normally recommended by the health service, were a major source of inspiration, which influenced participants' choice of treatment. After seeing personal stories from the community, participants would read medical literature, including work by medical experts advocating alternative diets, often by following weblinks shared in the community.

The community was also supportive of a culture of choice, whereby members were encouraged to find what suited them rather than being told what they should do:

*“[The forum has] helped me to make my own choices, not told me what I need to do, not told me what they think is right for me” (P49, T2D).*

One example is the advice to “eat to your metre” (i.e. test your blood glucose after meals), which the community would give to people with T2D. This is in stark contradiction with healthcare professional advice since clinical guidelines in England do not recommend such testing for people with T2D. Many participants with T2D showed frustration at this type of advice since it limited their choice and ability to control diabetes:

*“I have to pay for all my strips, [...] my meter, and everything else, because, as a type 2, they say, I don’t need to test. If I don’t test, I don’t know what works and what doesn’t work in my diet and, therefore, my sugar levels will go [up]” (P49, T2D).*

After experimenting with the OHC’s advice, people felt that the OHC was providing better choice over diabetes management than healthcare professionals:

*“[On the forum] there were a whole load of people saying [...], I have type 1 diabetes [and] I am finding it much easier to manage if I eat a much smaller amount of carbohydrates and fill up on fat instead [...] And I thought, this must be a load of rubbish, because my doctor has been telling me for decades take insulin, eat rice, potatoes, pasta, brown bread [...]. I started making changes to my diet, and I noticed that I wasn’t having the peaks and the troughs in my blood glucose control, I would still have insulin and I had to work out a different way of calculating my dosage based on the protein and the fat I was eating” (P23, T1D).*

Hence, there were evident contradictions between healthcare professional advice and the OHC’s advice. Next, we unpack how our study participants made their treatment decisions by

evaluating the OHC's advice against their healthcare professional advice and then choose what suited them best.

### **Choosing between community advice and medical professionalism**

We found three different decision strategies among participants. First, patient expertise was granted greater authority than healthcare professional expertise. In this way, participants could justify asking the community for advice as well as choosing the community advice instead of healthcare professional advice:

*“Who’s better to ask than someone who has it every day? [...], the doctor has gone to school to learn about [diabetes], and they get textbook rules, and it’s nothing like a living textbook, is it?” (P36, T1D).*

Second, they used their own independent judgement to evaluate the community advice, make treatment decisions, and validate treatment with experimentation. Knowing that “everyone is different”, participants would choose to try what they thought would suit them best:

*“[The forum’s advice] was actually medically sound [...]. The problem we have with diabetes is that everybody is different, so it takes a lot of trial and error” (P16, T1D).*

This sometimes meant choosing a path that was different from the path taken by most members of the community. One participant with T2D, for example, found out that a low-carb diet was not working for her and switched to a low-calorie diet instead:

*“What I have had to do is find my own path really, and I have found that [a low-calorie diet] is about the only thing that actually works long term for me. As long as I stick to it, I lose weight” (P24, T2D).*

A third strategy was to appropriate medical professionalism. Through this strategy, participants would use knowledge about medical facts and from medical research to evaluate healthcare

professional advice against the community advice. In the following example, one participant with T2D asks the community for advice about a drug her doctor has recommended. Despite the community's "cynicism" about this drug, she proposes a medical argument to justify her decision to follow her doctor's recommendation and take the drug:

*"[...] empagliflozin, [...] was only released in 2012, so there was a lot of people [on the forum] posting a lot of very clinical information about studies [...] and a certain amount of cynicism about how this drug [...] seemed to have jumped a lot of the testing requirements and had gone into human use very, very quickly [...]. The only reason I agreed to take it is because my kidneys and my heart are both in very good condition, [...] and I think that they can cope with it for a month or so [...], if it is able to drastically lower my blood sugar levels by getting rid of the glucose in my urine, then that's surely a good thing." (P14, T2D)*

By appropriating medical professionalism, participants were more inclined to reject their doctor's or nurse's advice if they could not find a logical medical justification for it. For example, a controversial issue on the forum was the prescription of statins against cholesterol for people with T2D. According to many participants with T2D, doctors would offer this advice to "tick a box" and comply with official clinical guidelines which recommended prescribing statins for people with T2D even with cholesterol in the normal range. After asking for advice on the forum, one participant with T2D decided not to take statins as recommended by his doctor:

*"I have read on the forum that statins raised your blood glucose levels, so I said to [my doctor] [...] 'Look, I am not sure about these statins because they raise my blood glucose, and the only reason you are giving them to me is because my cholesterol has fallen into a range that you don't like, because my blood glucose is raised. If my blood glucose was lower, you wouldn't be prescribing me with statins.'" (P13, T2D).*

This participant justified his decision on the basis that, in his view, his doctor's advice was illogical from a medical standpoint:

*“If my cholesterol had been high full stop, higher than normal for a normal average person, then I think I would have taken the statins, [...] I would have said to [my doctor], ‘[...] it makes sense, if that is your advice, I will take it’. It was the conundrum of, I am only getting the statins because my blood glucose is high, my blood glucose will be raised by taking the statins, I will probably need more statins, it just sounded illogical (P13, T2D)”.*

Therefore, when participants could not find a logical justification for healthcare professional advice even from a medical point of view, they would experience a greater tension between the logic of personal choice, concerning their right to choose the treatment that best suits their personal situation, and medical professionalism that underpins clinical advice given to patients.

### **Managing boundaries between epistemic domains**

Knowledge acquired through the OHC gave participants confidence to discuss treatment options with healthcare professionals. Sometimes advice shared in the community would help participants discuss and follow their clinic's recommendations:

*“I'd been, generally, quite averse to the whole concept of the insulin pump [...], and reading other people's experiences on [the forum] made me much more open to speaking to my clinic, and then I've now been on the pump for five years and it's totally changed my life.” (P40, T1D)*

Yet, other times, stories and resources shared in the community would encourage participants to choose options that contradicted their healthcare professionals' advice. When discussing these options, some participants were faced with little support from their healthcare professionals. This made them more determined to adopt passive resistance, ignore their healthcare professionals' advice, and follow the path they had chosen without arguing with their doctor or nurse:

*“What we do is what we call the nodding-dog system. [Doctors/nurses] tell us what to do, we nod and smile and then we come away and we assess what they’ve said and we accept whatever we think is right and we reject whatever we think is wrong, but we don’t get angry about it and we don’t complain to them” (P26, T2D).*

By adopting passive resistance, some participants were able to choose their preferred treatment and go against healthcare professional advice without compromising the relationship with their doctor or nurse. By contrast, other participants had attempted to discuss their treatment choice only to encounter resistance from their healthcare professionals. For example, one participant who had been successful in reversing T2D on a low-carb diet got irritated after his nurse insisted on the importance of carbohydrates in a diet:

*“I [...] tried to discuss [how I was controlling diabetes] with the practice nurse [...] – she just sat there and said, “We all need to eat carbohydrates; you can’t avoid carbohydrates in your diet” and I went, “Okay so if that’s where you’re coming from, we’ll just agree to differ because you’re wrong, I’m right” and I got up and walked out (laughs)” (P09, T2D).*

From the perspective of medical professionalism, the nurse’s idea about carbohydrates being an essential part of a healthy diet was justifiable since it followed public health guidance (or “EatWell Guide”) in England. Yet, from the patient’s perspective, the nurse’s response was an attempt to challenge the validity of his choice of cutting out carbohydrates from his diet even though, by doing so, he had been able to keep diabetes under control. Here the nurse used medical professionalism to challenge the patient’s choice and validity of his experience, causing a rift in her relationship with the patient.

By contrast, other participants were able to discuss treatment and maintain a good relationship with their healthcare professionals despite their different views on treatment. This was possible thanks to their healthcare professionals being willing to accept their choice, on the one hand,

and the patients accepting and justifying their healthcare professionals' point of view, on the other hand. In this way, both healthcare professionals and patients were able to neutralise tensions between medical professionalism and the logic of personal choice.

For example, one participant with T2D told his nurse about his decision to treat diabetes with diet with the aim of stopping medication. The nurse was supportive and helped the patient achieve his goal:

*“In the conversations I’ve had with my diabetic nurse, I’ve [...] been able to say, ‘Look, the research is this. If I can get my blood glucose levels down to the low 30s and then maintain them for six months, then I would like to try to come off metformin altogether’, and she was saying, ‘Yeah, I agree with you. [...]’ [...] I asked about having a blood glucose monitoring kit [...], and [she] said, ‘Well, we don’t really do that for type 2 diabetes, following the national recommendations.’ I said, ‘Well, I’m trying to work out which foods have the biggest effect on me,’ and she was saying, ‘Yeah, I think you’re actually...’ I think she was [...] worried that some people take the blood glucose kits and then don’t use them. However, she felt that I would use them, and we were able to chart certain things that had a disproportionate effect on my blood glucose levels. [...] that was the carbohydrate and sugar that was in them” (P47, T2D).*

In this example, by citing “research” to justify his choice, the participant was appropriating medical professionalism and overstepping into the nurse’s epistemic domain. Yet, the nurse did not turn defensive but supported the participant’s choice even by agreeing to provide him with a testing kit in breach of official clinical guidelines. While the nurse’s act may seem to contravene medical professionalism, the nurse was using her professional expertise to accommodate the patient’s choice to take control of his condition with diet, thus reconciling medical professionalism with the logic of personal choice.

Other ways in which participants could maintain a good relationship with their healthcare professionals and discuss treatment options with them was by drawing the boundaries between patient expertise and healthcare professional expertise. By drawing the boundaries of healthcare professional expertise, participants acknowledged the constraints to healthcare professional practice. For example, they acknowledged the fact that healthcare professionals could not fully commit to alternative treatments without an established body of research that could prove their health impact long-term. They were also sympathetic towards their healthcare professionals, arguing that they may be sanctioned if they did not comply with official clinical guidelines. By drawing the boundaries of healthcare professional expertise, participants could also set their own expectations of what type of advice they could receive from their healthcare professionals:

*“I would never go to a [doctor] for nutritional advice, in the same way, I would never go to a nutritionist to get a diagnosis for an appendicitis or thyroid problems” (P52, T2D).*

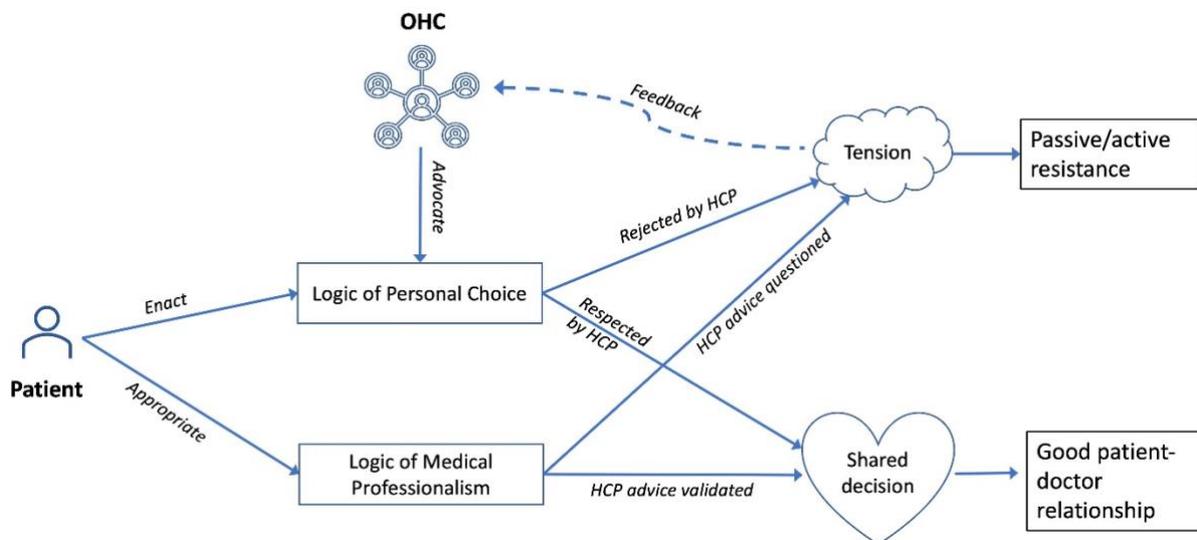
Likewise, participants drew the boundaries of patient expertise by acknowledging that healthcare professionals’ expertise is superior to patient expertise, particularly when it comes to medication:

*“I don’t use [the forum] for any information or advice anymore. I tend to find that if I’ve got a question now, it will be religiously regarding my insulin dosings, and I will go directly to my diabetes nurse [...]. I wouldn’t put that information onto the diabetes forum, and if people ask for that information on the forum, then I direct them straight to their diabetes nurse or consultant” (P08, T1D).*

Hence, on the one hand, overstepping into healthcare professionals’ epistemic domain by appropriating medical professionalism was a strategy that some participants adopted to evaluate healthcare professional recommendations against advice and information shared in

the community; on the other hand, participants made a clear-cut distinction between professional expertise and patient expertise. By doing so, they could maintain a good relationship with their healthcare professionals, even when their expectations under a logic of personal choice clashed with healthcare professional advice. Drawing the boundaries between professional expertise and patient expertise also guided what type of advice they were willing to share on the forum.

We summarise our main findings in Figure 1 and Table 3.



**Figure 1. The dynamics of the Patient-Doctor Relationship influenced by the OHC**

Patient's strategy	Patient's decision-making	Doctor's response	Patient's Response	Patient-doctor Relationship
Invoke patients' (as a collective whole) epistemic authority	OHC expertise is granted greater authority than healthcare professional expertise	Challenge patient expertise and OHC authority	Active resistance	Rift in healthcare professional-patient relationship
Enact the logic of personal choice	Adopt OHC advice in making treatment decisions; Validate treatment choice with experimentation	Sceptical of OHC advice but respect personal choice	Passive resistance	Patient chooses preferred treatment against healthcare professional advice
		Recognise patient and OHC expertise; Give patients choice/control	Draw boundaries of medical expertise; recognise constraints of medical professionalism in	without compromising the relationship

			healthcare practice; set expectations about professional medical advice	
Appropriate medical professionalism	Review medical evidence and medical research to evaluate both OHC advice and professional advice	Reconcile medical professionalism with logic of personal choice; recognise validity and limits in both patient/OHC expertise and medical professionalism	Reconcile medical professionalism with logic of personal choice; recognise validity and limits in both patient/OHC expertise and medical professionalism	Both sides neutralise tensions between logics of medical professionalism and personal choice, maintaining good patient-doctor relationship

**Table 3. Summary of Findings**

## Discussion

This study has confirmed the role of OHCs in promoting a logic of personal choice by exposing patients to alternative treatment options and encouraging self-management, thus creating tensions with the logic of medical professionalism that legitimises healthcare professional advice. In answering our research question, we have shown how patients deal with tensions between these two logics, and the consequences that this may have for their treatment decisions and relationship with their healthcare professionals.

Our first contribution is to show how both logics are influential of patients' treatment decisions. In line with previous research (e.g., Bellander and Landqvist, 2020), we show how OHCs mix knowledge from medical research with patients' collective experience. On the one hand, patients' collective experience with an illness represents the logic of personal choice since it is a source of legitimacy of the OHC's advice as well as patient autonomy in experimenting and choosing what is best for them (Kitson et al., 2013; Lemire et al., 2008). On the other hand, patients appropriate medical professionalism by drawing on medical research to evaluate healthcare professional advice against the OHC's advice. These findings explain differences in how patients' interactions with OHCs influence the patient-doctor relationship, specifically,

why some patients may defer to healthcare professional advice against the OHC's advice (Brady et al., 2016) or, *vice versa*, prefer the OHC's advice to healthcare professional advice. By appropriating medical professionalism, patients evaluate both types of advice from a medical standpoint. As shown in our study, patients prefer healthcare professional advice when they can find a logical medical explanation to it even though this means going against the community's advice. By doing so, patients can even defeat scepticism raised by OHCs against the validity of scientific evidence about treatment recommended by healthcare professionals, suggesting that by appropriating medical knowledge (Keeling et al., 2013), patients may not necessarily contribute to the spread of misinformation (Bellander and Landqvist, 2020). On the contrary, they may reduce the risk of misinformation by neutralising scepticism against medically sound treatments.

However, medical professionalism is not simply about medical knowledge but includes what knowledge is conventional and institutionalised and therefore informs clinical practice, often through governance mechanisms such as clinical protocols. In this respect, our study has shown that the appropriation of medical professionalism may raise scepticism when a logical medical explanation of conventional healthcare professional advice is not found. In this case, the OHC may have more influence on patients' treatment decisions and relationship with their healthcare professionals since patients may experience greater tension between the OHC's logic of personal choice, represented by their right of choosing the treatment that best suits them, and medical professionalism, represented by general clinical advice given to a patient population. Previous research has already shown how patients trust experiential evidence co-produced by OHCs more than statistical evidence proving the effectiveness of a treatment on a population (Broom and Tovey, 2007; Whelan, 2007). Our study adds to this research and shows that, in addition to the point of view of their own experience and the experience of members of an OHC, patients, collectively with the OHC, may scrutinise healthcare professional advice from

a medical standpoint. In the specific example presented in this study, the patient agreed with the OHC's advice and concluded that clinical protocols guiding their doctor's treatment recommendations did not make sense from a medical point of view. These protocols constitute the basis of norms of medical professionalism. By questioning the validity of these protocols, patients and the OHC they belong to are effectively shaking the normative foundations of medical professionalism. This example shows how patients' participation in OHCs can potentially augment patients' mistrust in clinical advice and undermine the relationship with their healthcare professionals.

In this respect, our second contribution is to show how patients deal with tensions between the logic of personal choice advocated by OHCs and medical professionalism governing the practice of healthcare professionals, and what implications this has for the patient-doctor relationship. Research in this area shows both a positive and negative impact of patients' participation in OHCs and consumption of online health information on their relationship with healthcare professionals (Dedding et al., 2011; Rupert et al., 2016; Townsend et al., 2015). We extend this line of research by showing how these different outcomes stem from healthcare professionals' and patients' response to tensions between the logic of personal choice and medical professionalism.

First, we demonstrate how healthcare professionals' reaction to patients' logic of personal choice promoted by OHCs may trigger different forms of patient resistance. Like Landmark et al. (2015), we found that patients respond to healthcare professionals' opposition to the logic of personal choice, manifested through their lack of support of patients' choice, with passive resistance. Contrary to what suggested in previous research (e.g., Broom, 2005), by refraining from discussing the OHC's advice and online health information with their doctor through passive resistance (Stevenson et al., 2021), patients can still be empowered by choosing their preferred treatment without compromising the relationship with their healthcare professionals.

On the other hand, we show how healthcare professionals' use of medical professionalism in challenging patients' choice and validity of their experience is met with active resistance by patients, thus creating a rift in their relationship with the patient, even though unwittingly. Therefore, by adopting confrontational responses to patient resistance (Stivers and Timmermans, 2020), healthcare professionals may augment rather than neutralise patient resistance and further compromise patients' trust in healthcare professionals (Fujioka and Stewart, 2013).

Second, apart from passive resistance, we reveal more proactive strategies that patients adopt to maintain their right to choose under the logic of personal choice while still maintaining the relationship with their healthcare professionals. Through these strategies patients can benefit from the OHC's advice without interfering with or openly challenging their healthcare professionals' epistemic domain and deontic rights (Lindström and Weatherall, 2015), representing respectively a source of legitimacy and authority of medical professionalism. At the same time, we show how these strategies are possible thanks to the collaboration of their healthcare professionals by supporting patients' choice and recognising their expertise, thus reinforcing arguments about the empowering effect of healthcare professionals' engagement with patients' decision making (De Rosis and Barsanti, 2016). For example, one patient's attempt to overstep into the epistemic domain of medical professionalism was met with support by their healthcare professional. This healthcare professional was able to reconcile medical professionalism with the patient's logic of personal choice, thus preserving their relationship with the patient.

Finally, by drawing boundaries between medical expertise and patient expertise constructed by OHCs, patients acknowledged constraints and limitations on both sides and neutralised tensions between medical professionalism and the logic of personal choice. Patients were thus able to maintain a good relationship with their healthcare professionals, even when their

expectations under a logic of personal choice clashed with healthcare professional advice. This strategy also guided what type of advice patients were willing to share with the OHC. It thus constitutes a self-regulating mechanism through which patients establish what advice is safe and appropriate to share on top of existing safeguards already present in OHC such as (peer-) moderation, often reflecting a shared culture within the community.

## **Conclusion**

Despite decades of academic debate on the role of the Internet in “democratisation of healthcare”, there is still limited research on how members of OHCs manage potential tensions in the patient-doctor relationship engendered by the online community interactions. Taking an institutional logic perspective, this study fills the gap through studying how active members of an OHC for diabetes enact different logics in weighing treatment options and in managing their relationship with doctors. Our findings suggest that many patients exercise a great deal of agency in navigating health options not only by activating the logic of personal choice but also by appropriating the logic of medical professionalism. While we concur with the existing literature that OHCs in general promote the logic of personal choice, often portraying healthcare professionals as conservative and paternalistic, we also find evidence that OHC members appropriate the logic of medical professionalism in deciding what personal experience to share on the OHC and what community advice might be problematic. In sum, compared to many previous studies that emphasise patient consumerism fuelled by information on the Internet (Fox et al., 2005; Tan and Goonawardene, 2017), our study provides a more nuanced picture of patient-doctor relationship engendered by patients’ participation in OHCs. Just like healthcare professionals “transgressed the borders of professionalism” earn high trust from patients (Vale and Good, 2020), patients embracing both personal and professional logics

are likely to develop a productive relationship with their doctors while at the same time benefitting from interacting with other patients online.

There are limitations to our study that merit consideration and future research. First, our study of patient-doctor relationship takes the patient perspective only without input from healthcare professionals. It would be interesting to examine how healthcare professionals enact different logics when facing “Internet-informed” patients in the context of chronic illness care. The juxtaposition of the two perspectives may highlight gaps and consensus on the use of OHCs and its impact on the patient-doctor relationship (e.g., Atanasova et al., 2018). Second, as patients usually do not distinguish different types of healthcare professionals, we also lump together GPs, nurses, and diabetes specialists in our data collection and analysis. Fine-grained analysis of variations across types of healthcare professionals in terms of their adherence to the medical professional logic and how they perceive and react to OHCs might be another promising direction for future research. Lastly, our study drew a sample from one OHC only. The observations we have made in this study might not be directly applicable to OHCs for other health conditions such as cancer, for which choice over treatment is limited, and OHCs that involve both doctors and patients (Liu et al., 2020) where the dynamics of personal choice and medical professionalism may play out differently.

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## **Appendix**

### **A1: Interview schedule**

1. When did you start using the forum and why?
2. How often do you visit the forum and how much time do you spend on it?
3. Do you write any posts on the forum? Can you give an example of any post you have written recently and the type of responses you have received?
4. Were you finding it difficult to cope with diabetes before joining the forum? Could you please give examples?
5. Has the forum helped you overcome such difficulties? In what ways?
6. Do you believe in everything that is shared or said in the forum? Could you please give an example of any information shared on the forum that you thought could not be true and, vice versa, an example of information shared that you didn't think could be true?
7. How do you make sure that you can trust the information shared on the forum? Please give examples.
8. Who do you normally see for the care of your diabetes in the health service? (Is it your GP/nurse?)
9. Are you satisfied with the relationship with your GP/nurse and the type of medical advice you receive? Can you please illustrate with an example?
10. Do you think the information shared in the forum differs from your doctor's or nurse's advice? In what ways?
11. Do you feel empowered (in managing diabetes)? In what ways?
12. Has the forum played a role in the way you feel empowered? Can you provide an example of how this has happened?
13. Have you developed a strong connection with any of the members in the forum? (e.g. people with whom you interact more or whose posts you read or follow more?) – no need to name them. Can you explain how you interact with these members? For example, what is the information that you read from them or share with them? How have the relationship with these members or the online discussions with these members helped you?
14. Apart from having diabetes, what do you think the people that visit the forum have in common?
15. From a scale from 1 to 10, how important is the forum for you? Could you please explain its importance with an example.
16. Could you provide the following information:

Age:

Sex (*M or F*):

Years (or months) with diabetes:

Type of diabetes:

## A2: Coding scheme

First-order code	Second- order code	Aggregate theme
Bad relationship with diabetes nurse	Dissatisfaction/Bad relationship with HCP	Bad doctor-patient relationship
Complain with/about doctor/nurse over different views on treatment/handling of consultations		
Disparage HCPs		
Forum builds consensus around argument against clinical advice by citing influencers' work	Forum challenges mainstream medical advice/theories	Community challenges medical professional logic
Forum challenges official dietary advice based on medical facts		
Forum questions integrity of science/evidence guiding clinical advice		
Many people on forum don't like statins		
Forum criticises HCP/NHS for not being up-to-date		
Forum encourages members to go against clinical advice and guidelines		
Forum gives confidence that you can live a normal life with diabetes	Forum gives confidence/independence	Community gives choice (logic of personal choice)
Forum gives confidence that you can manage/control/treat your own diabetes		
Forum gives confidence to decide whether to follow/not to follow HCPs' advice		
Forum gives confidence to try new things (even against clinical advice)		
Forum has more radical/progressive advice than health service	Forum is progressive/life changing	
Forum is a life-changing/life-saver		
Mindshift about diet/treatment	Forum influences treatment beliefs/decision	Community influences patient choice
Low carb works because people/forum members can prove it with their own experience		
Question one's treatment after finding out that forum members are treated differently		
Forum members' testimony confirms/gives confidence about initial beliefs about treatment/illness		
Start low-carb diet after reading forum advice		
Try tips/solutions from members who are experiencing the same problems		

Decide to try low-carb after reading success stories/medical results on forum		
Do not follow clinical advice on medication/testing based on forum's stories	Disagree with HCP based on forum testimony	Community influences patient choice to challenge medical professionalism
Forum success stories/testimony prove that official/clinical advice is wrong		
Forum members encourage to eat to your metre/use of food diary	Forum encourages personal choice	Community promotes logic of personal choice
Forum lets you decide what is best for you		
Members give suggestions based on their own experience (It worked for me, it might not work for you)		
Change of healthcare provider/doctors, better relationship	Good relationship with HCP	Good doctor-patient relationship
Do not feel intimidated to pose questions to nurse		
Good relationship with nurse/doctor		
Doctor/nurse is supportive of patient's choice	HCP accepts/respects patient choice	HCPs accept logic of personal choice
Nurse is not fully supportive of patient's choice, but acknowledges the good results		
Nurse/doctor is supportive of me doing low-carb, but with caution		
HCPs do not involve patients in treatment decisions/be paternalistic ('do what we say')	Paternalism	HCPs do not give patient choice/control
Doctor/nurse do not give/explain test results		
Health service makes me look 'non-compliant'		
Find more help (about diet) from forum than from doctor/nurse/dietician	Little HCP support about diet/self-management/living a normal life	HCPs do not give patient choice/control
Find more help from the Internet and self-management than from clinical advice		
Health service does not understand dietary requirements of a PwD		
No/little support to self-management/how you can improve your health/live a normal life		
Advise against testing	HCPs are anti-low-carbs and anti-testing	HCPs follow medical professionalism against logic of personal choice
Doctors follow a dogma about starchy carbohydrates		
Doctors/nurses think that cutting out starchy carbs/high-fat is dangerous		
Recommend diet high in carbs (Advise against cutting carbs)	Medicalised approach to diabetes	HCPs follow medical professionalism against logic of personal choice
HCPs believe that diabetes is a progressive disease (to be managed with drugs)		
Overprescribing of medication		
Doctors focus on the medical side of diabetes		

Health service gives patients control over their health	HCPs give patients control		
Doctor promotes collaborative care	Collaborative care	HCPs give patients choice/control	
HCPs listen to understand patients' needs (collaborative care)			
HCPs do not learn/change practice from patients' experience/are not open minded	HCPs are not open minded	Medical professionalism is conservative*	
Doctors do not acknowledge latest scientific theories/science on low-carb			
HCPs do not admit that their clinical advice is wrong			
HCPs have a conservative take on things (they are cautious)	HCPs are cautious		
Skepticism about low-carb diet	HCP practice is outdated/regressive/bureaucratic		
HCPs' knowledge/official clinical advice/reaction to new treatments is outdated (not up-to-date with research)			
HCPs are rigid in their thinking			
Doctors treat the symptoms but not the causes of a chronic disease			
Medical practice is a ticking box exercise			
Doctor trusts patient expertise	HCPs recognise patient expertise/achievements		HCPs recognise patient expertise/achievements
HCP acknowledge patient's success in controlling diabetes			
Doctor/nurse is not supportive of patient's choice	HCPs Do not accept/respect patient choice	HCP agency: reject logic of personal choice	
Nurse disapproves of forum			
Nurse/doctor advises to be cautious and verify forum information			HCPs and the Internet: Disapproval, scepticism, antagonism
HCPs disapprove of social media/Internet information			
HCPs discourage patients from seeking support from OHC			
Doctors play the science card to delegitimise patients' testimony about alternative treatments	Use medical professionalism to defend one's authority		
Justify new diet/change in diet based on medical facts	Justify diet/treatment choice based on medical research/facts		Patients appropriate medical professional logic
Make/justify diet/treatment decision/choice based on medical research			
Conflict of opinion about diabetes being a progressive disease	Conflict of opinion with HCPs over nature of disease		Patients challenge medical professionalism
Conflict of opinion about hypos			
Disagree with HCP/official dietary advice based on BS readings	Disagree with HCPs		
Disagree with clinical advice on salt based on someone else's personal experience			
Refute scientific results of mainstream diet based on personal medical results		Distrust science supporting mainstream diets	
Science guiding mainstream clinical advice is bad/wrong/untrue			
Being sceptical about clinical advice/lose faith in HCPs	Distrust Clinical advice	Patient agency: do not trust clinical advice	

Clinical advice is bad/wrong/nonsense		
Have poor opinion of some of the doctors		
Experiential knowledge/forum testimony has limitations/ not scientific	Acknowledge limitation of experiential evidence/patient expertise	
Acknowledge limitation of personal judgement/opinion (vs medical facts)		
Forum members are credible (not experts)	Forum members cannot/should not give medical advice	Draw boundaries of patient expertise
People on the forum cannot/shouldn't advise about medication (you should ask a HCP)		
Do not give medical advice		
Advise support seeker to see their HCP	Value medical expertise (vs patients' knowledge)	
Doctors are the experts, I am an educated patient		
Trust official medical information/clinical advice more than ordinary people on forum		
Doctors are the experts, PwD are amateurs		
Expertise of medical profession is always needed		
Listen to doctors since they are trained professionals/experts	Understand limits of medical practice/expertise	Patients draw boundaries of HCP expertise
HCPs do not go against conventional advice to comply with official guidelines/safeguard their credibility/career		
HCPs are professionally trained - they are taught what to say		
Patients understand constraints to doctors' practice		
Doctors deal with medical side, but cannot advise on nutritional side		
Doctor/nurse has limited knowledge about diabetes	Do not argue with doctor/nurse	Passive resistance to clinical advice
Do not argue over doctor's advice due to insufficient knowledge		
Do not confront HCPs over contrasting views		
Feel intimidated to argue/share treatment decision with HCP		
Ignore HCP advice	Passive resistance	
Nodding dog system		
Consult with HCPs about change of diet/goal to reverse diabetes	Trust HCP advice	Patients trust HCP advice
Consult with HCPs about forum information		
Consult with HCPs about medication/for medical help		
Trust HCPs' advice		
Forum members build trust by posting medical history in their profile/signature	Trust forum members from their medical results	Trust patient expertise

Judge forum members' credibility/competence by their medical test results/blood readings		
Trust forum members' testimony based on experiential evidence		
Forum is (more) up-to-date with current knowledge (than HCPs)	Value forum members/patient knowledge/expertise (more than medical expertise)	
Lived experience has more value than doctors' theoretical knowledge about diabetes		
People on the forum are well educated about their own condition		
Prefer forum advice to clinical advice		

### A3: Classification of participants by type of P-D relationship

Groups	Participants	N. of Participants with T1D	N. of Participants with T2D	Total N. of Participants
G1: bad relationship with HCPs	P09, P11, P12, P21, P24, P28, P33, P53	1	7	8
G2: do not feel supported by health service but trust HCPs	P08, P25, P36, P43, P48	5	0	5
G3: good relationship with HCPs	P10, P16, P18, P20, P22, P23, P27, P29, P30, P31, P34, P35, P37, P38, P40, P41, P42, P44, P45, P47, P50, P52	14	8	22
G4: good relationship with HCPs but critical of conventional medical advice	P13, P14, P17, P19, P26, P39, P46, P49, P51	0	9*	9

\* Includes one carer of a person with T2D