BMJ Open

Patients' recording clinical encounters. A path to empowerment?

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2015-008566
Article Type:	Research
Date Submitted by the Author:	21-Apr-2015
Complete List of Authors:	Elwyn, Glyn; The Dartmouth Institute for Clinical Practice and Health Policy, Barr, Paul; The Dartmouth Institute for Clinical Practice and Health Policy, Grande, Stuart; The Dartmouth Institute for Clinical Practice and Health Policy,
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Evidence based practice, Health services research, Health policy, Patient-centred medicine
Keywords:	MEDICAL ETHICS, MEDICAL LAW, QUALITATIVE RESEARCH

Patients' recording clinical encounters. A path to empowerment?

Glyn Elwyn, Paul James Barr, Stuart W Grande

The Preference Laboratory
The Dartmouth Institute for Health Policy and Clinical Practice
Dartmouth College
Hanover
New Hampshire USA 03755
Glyn Elwyn, professor
Paul Barr, assistant professor
Stuart W Grande, postdoctoral researcher

Corresponding author: Glyn Elwyn glynelwyn@gmail.com

The Dartmouth Institute for Health Policy and Clinical Practice
Dartmouth College
Hanover
New Hampshire USA 03755

Word count – excluding tables / figure 4213

Abstract

Objective To examine the underlying motivations and frequencies of patients who recorded clinical encounters, covertly or otherwise, and for those who have not yet recorded encounters.

Design A mixed methods study, including a quantitative analysis of cross-sectional survey data and a qualitative analysis of nested semi-structured interviews.

Setting Survey advertised to UK audience, using social media and radio broadcast.

Participants 168 participants, aged 18 years or older, responded to the survey, of which 161 were eligible (18 years of age or older), and 130 completed the survey. Of the 56 participants who agreed to be contacted, we included data from 17 interviews.

Results Nineteen (15%) respondents indicated having secretly recorded a clinical encounter and 14 (11%) were aware of someone who had secretly recorded a clinical encounter. Forty five (35%) said they would consider recording a future health care visit secretly, and 44 (34%) would do so after asking permission. So, of this sample, a total of 69% of respondents indicated their *desire* to record clinical encounters, split equally between want to do so covertly or with permission. Data from 17 interviews enabled the development of a thematic representation of this phenomenon. Most are motivated by the wish to replay, re-listen and share the recording with others. Some others are also motivated by the idea of owning a personal record, and its potential use as verification of a poor healthcare experience. The decision to seek permission to record or to do so covertly revealed crucial distinctions. The rationale for asking permission was founded on the wish to prioritise and protect a trusting relationship with a health professional, making the increased accountability of recording open and public. Those who preferred to record covertly described a pre-existing lack of trust, a fear that recording would be denied, and a concern that an affronted clinician would deny them access to future care. There was a wish for normalization: that recording be facilitated, if desired by the patient.

Conclusions Some patients are considering using portable technology, such as smartphones, to capture a record of clinical encounters. Their prime motivation is to enhance their experience of care, and to share it with others, although it is also clear that many realize that the data could also be used for verification, if required. Patients are generally concerned that their wish to record challenges the "ceremonial order of the clinic", and so some decide to act covertly. Patients wanted clearer, more permissive policies to be developed.

Strengths and limitations of this study

- This study is the first to estimate the extent to which patient recording of medical encounters, covert or open, is occurring in the UK and motivations to do so.
- The mixed methods design is a strength of this project
- A convenience sample was used, which limits the generalizability of the results
- Themes derived from patient interviews were triangulated with open comments made on the survey

Introduction

Mobile technology has become pervasive; it is no surprise that it has found its way into medical encounters, with reports of patients recording clinical encounters using either smartphones, or other devices. Some ask permission and others do it covertly [1]. The behavior is new, facilitated by devices that make this easy. It may also indicate the development of a new attitude towards what has been called the 'ceremonial order of the clinic'[2], challenging the established etiquette of a deferential and subservient patient norm.

There are studies of clinicians deciding to offer recordings to patients, particularly in paediatrics and in oncology, where complex, emotional subjects are discussed, and information given which is especially difficult to retain. A recent review showed that patients valued the ability to re-listen to the recordings, often doing so more than once, as well as being able to share recordings with their family [3]. A more recent study also found statistically significant reductions in decisional regret for patients with access to recordings [4]**.** These benefits could be of value to patients, particularly to those with low literacy, although there is a lack of research on this issue [35]. In mental health and family medicine settings, recordings have been used for clinical training. Where recordings have been shared with patients, their use as adjuncts to therapy has been reported [6].

Despite the documented benefits associated with clinicians offering recordings to patients, routine recording of clinical encounters is uncommon. Now patients are deciding to record encounters themselves, some doing so covertly [7]. Clinicians are becoming aware of the possibility of being recorded and are concerned that the recordings, especially those that are covert, would be used for litigation purposes [7]. Policy makers have begun, for the first time, to provide guidance to patients who are considering covert recording [8].

Although the topic of covert recording has been the subject of recent debate [19], we could find no research that has investigated the phenomenon of patients deciding to record their own clinical encounters. The aim of this study was to explore this behaviour, to estimate to what extent it is occurring or is desired, and to understand more about why individuals are motivated to record and how they navigate the decision to do so by seeking permission or by acting covertly.

Method

Survey design and participants

We administered a cross-sectional survey online, after an interview broadcast on BBC Radio 4 (July 8th, 2014). In the program, one of the study authors (GE) talked about the pros and cons of patients recording their clinical encounters. The opportunity to complete a survey about this topic was announced and advertised on the programme website, and through social media. Respondents, over the age of 18, were asked three closed-response questions about their experience and views of recording encounters with a health professional: 1) Have you ever secretly recorded your encounter with a health professional? 2) Would you consider secretly recording your encounter? 3) Would you like your clinic to allow you to record your encounters? We included questions about age, gender, education, country of residence, and whether English was the only language spoken at home and space was given for further comments.

Quantitative Data Analysis

Categorical responses of respondents from the UK were summarized. Where appropriate, Pearson's chi-square test of independence was used to identify statistical association between categorical variables. Where cell counts were under five, we used Fisher's exact tests. Hypothesis generating multiple logistic regression analyses were conducted to explore respondent characteristics associated with the act of covert recording, compared to all other respondents. We also conducted an analysis comparing the characteristics of individuals who would record a medical encounter with permission to those who would covertly record. All analyses were adjusted for age, gender, language spoken at home and education. Analyses were conducted using STATA, Version 13.0, StataCorp, College Station, Texas.

Qualitative interviews

We contacted respondents who had provided an email address in the survey and conducted semi-structured interviews with consenting participants using an agreed schedule (Appendix 1). We purposefully sampled respondents based upon survey responses: 1) have covertly record; 2) would covertly record; 3) would only record with clinician's permission; and 4) have no interest in recording.

We developed the interview schedule *a priori,* making modifications based on the respondents' experience of covert recording, or willingness to record, covertly, with permission or not at all. The interview covered the following topics: experience of recording or willingness to record, and their motivations do so covertly, with permission or not at all; perceived benefits and possible negative consequences of recording, both overt and covert, and the consequences and experiences of requesting permission to record. Attention was given to the issues raised at preceding interviews, enabling further probing into salient topics and concerns, consistent with a grounded theory approach. All interviews were conducted over the telephone, recorded and transcribed.

Data Analysis

Before embarking on qualitative analysis of the interview transcripts, two researchers met (SG and PB) and developed an initial codebook, based on the interview questions [10]. This process informed a thematic analysis of interview transcripts where initial codes are grouped by salient themes. Independent coding was completed with the initial codebook. Emergent codes were added, and existing codes revised where necessary. PB & SG met to discuss and assess potential additions to the codebook; disagreements were discussed and resolved. A second coding process was undertaken to apply the revised codebook to the data. Codes, memos, short narrative summations of data, were entered into a spreadsheet for further discussion with a member of the research team who had also read the transcripts (GE). By critically reviewing the codes and associated memos, the data were categorized using a conceptual mapping process [10]. We checked the categorization by comparing the open-text survey comments to the interview data [11].

Results

A total of 168 individuals responded to the survey. Seven were under 18 years old, and therefore ineligible. Of the 161 eligible respondents, 130 completed the survey. There were no significant differences in gender, age or educational attainment between individuals who completed the survey and those who did not. A description of respondent characteristics can be found in Table 1.

Do people secretly record their medical encounters?

Of the 130 complete respondents, 128 answered the questions regarding their experience and views on covertly recording a visit with a health professional (Table 2). In this sample, covert recording had been performed, or known about, by 33 (26%) respondents. A total of 19 (15%) respondents reported secretly recording a medical encounter, with a further 14 (11%) respondents, reporting that they personally know of someone who has secretly recorded an encounter. When asked if they would consider recording a medical a visit with a health professional, 45 (35%) respondents stated that they would, and a further 44 (34%) indicated a willingness to record only after asking the clinician for permission. Finally, 98 (77%) respondents indicated that they would like their clinic to allow recordings of medical encounters.

Recording covertly or with permission.

Multiple logistic regression analysis indicated that among respondents, individuals who reported making a covert recording were more likely to be male, OR 3.6 (95% CI 1.16 to 11; P=0.03) and have less than a university education, OR 5.5 times (95% CI 1.35 to 22.4; P=0.02). A second analysis indicated that individuals who would only record with permission from the clinician, compared to those who would covertly record, were more likely to have a university education, OR 11.1 (95% CI 2.1 to 60.6; P=0.004).

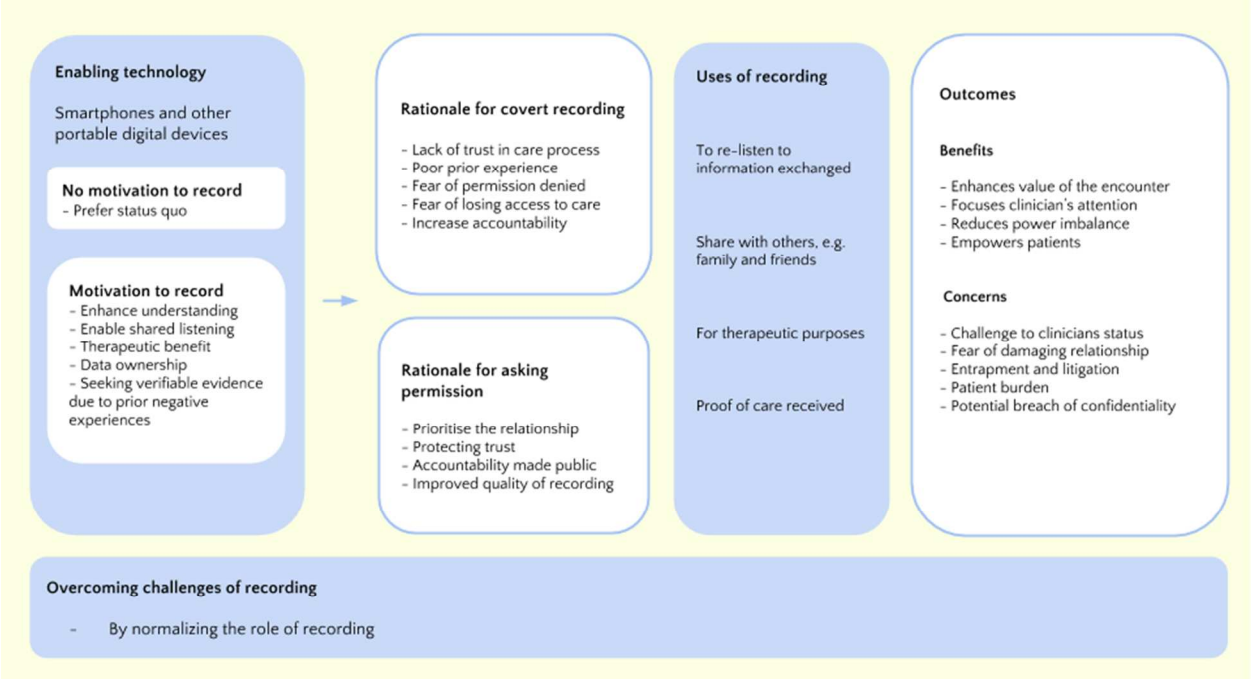
Qualitative Analysis

Out of the 130 respondents who completed the survey 56 agreed to be contacted. Of those 56, 21 consented, and 18 were interviewed. We excluded data from one respondent who was not from the UK. We included data from 17 interviews, 10 women and 7 men, all of whom had college (or higher) levels of education; 70% were 41 years or older, and all spoke English at home, save for one individual (for details, see Appendix 2). Three of the interviewees had covertly recorded in the past, six interviewees would consider secretly recording, seven interviewees would only record with permission, and two interviewees would not record. Figure 1 provides a thematic representation of the interview data.

It was evident that the availability of digital technology had to a large extent facilitated patients to consider recording clinical encounters, as one individual said: *"we've all got devices that are portable and easy to record*

with" (Interviewee 1). Although not all patients will want to make use of the capability, smartphones and other devices can be used with minimal disruption, making covert recording possible. Patients described their motivations to record, and their rationale for either asking permission or acting covertly. They also described how they made use of such recordings, including the associated benefits and concerns. A recurring concern was that recording would violate the etiquette expected in clinical encounters, a deviation from the passive role of the patient. Consequently, many patients volunteered that the solution to this tension would be to 'normalise' the behaviour, to make it part of usual practice. After the interview data were analysed, we compared our findings to the 76 open-text comments in the survey, and found no new themes.

Figure 1 Thematic data representation



Motivations to record

We ascertained five prominent reasons that motivated patients to record clinical encounters. The chief motivation for patients to record was the desire to enhance their understanding of the encounter, and in addition, to share their experience of the encounter with others, particularly when the problems and treatments were complex. There was one instance of a patient describing a therapeutic motivation, where re-listening to the encounter was viewed as an additional and complementary therapeutic input. The less explicitly stated motivation was to have a sense of data ownership, that the experience was somehow more tangible by being on record, acting essentially as a *"backup for my brain"* (Interviewee 17), and was in their possession: *"So my real motivation for doing the recordings was so that I had a record of what they were actually doing, what they were saying"* (Interviewee 7). In some instances, this sense of ownership was motivated by prior negative experiences, and the wish to have verifiable evidence of such an experience, should it recur.

Once a patient has decided to record an encounter, they come to a crossroads, should I record covertly or with permission?

Rationale for covert recording

Decisions to record covertly were based on concerns about negative consequences. Interviewees, keen to obtain a recording, had considered asking for permission yet had acted covertly due to a fear of being denied permission. Interviewees felt it was easier *"to apologize later"* rather than *"deal with the refusal"* (Interviewee 14). A interviewee who was also a clinician, also acknowledged this fear: "*I think it's quite possible that my clients might*

have recorded something, an interview with me, without telling me, possibly if they thought I might say no" (Interviewee 2).

Fear of denial was related to the worry that clinicians would be affronted by requests to record, to the point of asking patients to leave their care, a particular concern for those living in rural areas with limited options. One interviewee started out recording with permission, but after "*being threatened with removal from the practice*" (Interviewee 8) began to record covertly.

Another factor leading to covert recording was experiencing *"jaw-droppingly awful treatment"* (Interviewee 8), and wanting to have evidence of such an event. Interviewees felt that without such evidence, it was a situation of "*his word versus yours"* (Interviewee 9), and as "*the doctor can never be wrong"* (Interviewee 9), it was necessary to have "*actual tape recorded evidence... to protect yourself* [the patient]*"* (Interviewee 17).

One interviewee mentioned their experience of using the recording as evidence of bad care and said that it had led improvement in the quality of their next encounters: *"[I] put in the complaint, [and] that I [the patient] have a tape recording of the conversation*". When asked about the clinic's reaction, the interviewee stated that "*no mention was made* [to the recording] *in the reply",* and since the complaint had been placed, that their "*treatment there has been exemplary"* (Interviewee 14).

Rationale for asking permission

The majority of interviewees indicated a desire to record with permission. Maintaining and protecting the relationship with their clinician was a priority: "*It's a real partnership thing, isn't it?"* (Interviewee 16). They feared that covertly recording an encounter "*would be a breach of trust*" (Interviewee 12) between the patient and clinician, and that as a patient, "*you owe the clinician an explanation*" (Interviewee 13) for wanting to record. Interviewees felt like recording and "*not asking permission would be like subterfuge*" (Interviewee 1). One interviewee who been covertly recording indicated their discomfort and regret of recording without permission, to the extent that they were considering changing their stance.

Several interviewees felt that obtaining permission would have more impact, and lead to greater benefits, "*... because as I say, the physician would know that there was accountability*" (Interviewee 17). Whereas, "*If you do it covertly, they [the clinicians] wouldn't know would they, so I don't think it would change what was said in the room"* (Interviewee 6). Acting covertly would they argued lead to only "*getting half of the benefit out of the recording*" (Interviewee 8). Requesting permission was also viewed as a means of increasing mutual respect: "*I think if it was done openly, and with agreement to both parties, I think it could help develop more trust in the relationship*" (Interviewee 12). In addition, on a purely practical level, gaining permission enables a device to be used openly, facilitating a "*... better quality recording*" (Interviewee 14).

Use of recording

Those interviewed described four distinct uses of the recordings. Re-listening was the prime use, "*... to help me better understand what they said, because sometimes they talk so quickly"* (Interviewee 15*).* The ability to share the recording with others was very important to many individuals. One mentioned that the recording could be used for therapeutic purposes, particularly if the clinician was prepared to collaborate and support such a goal. The recording could also be used as proof of care received, with the clear implication that such data could constitute evidence of unsatisfactory care, should such a situation occur.

To re-listen to information exchanged

Interviewees who found it difficult to recall clinical encounters, were often unable to follow what was said, either because it was unclear, or delivered too quickly. It was widely felt that even though a patient might refer "*back to it* [the recording] *once or twice...* [many] *just found it useful to have as a reference*" (Interviewee 7)

Share with others

A common frustration reported by patients was an inability to give a good account of their clinical encounter. Interviewees acknowledged the significant benefit of: "*... bringing people into the process*" (Interview 4) by replaying the recording. This was viewed as a more reliable way of ensuring that others were able to understand the advice given, and as help to "*follow whatever instructions were provided*" (Interviewee 13).

For therapeutic purposes

An unexpected use of a recording was to revisit "*the emotion of the conversation*", to re-listen to the "*tone of voice*" to "*get all that reassurance and attachment stuff*" (Interviewee 5). This therapeutic use of the recording was made possible by the ability to replay the encounter: *"... when I listen back, I feel very supported and validated by those little things which I've missed first time round ... that sorts of reinforces the benefits of the therapy*" (Interviewee 5).

Proof of care received

The interviews indicated there was a desire by some to use the recordings as proof of interactions experienced. This was triggered by a sense that without having proof, concerns had too often been dismissed in the past: *"I think it could have helped to support my story of what happened"* (Interviewee 16). Patients reported the need to have verification, and that if they were unsatisfied, their word alone was insufficient: "*When you're experiencing poor engagement with your clinician ... it* [a recording] *would be really useful as a kind of evidence*" (Interviewee 6). A recording was viewed as less open to dispute: "*... he was being unsupportive, he said the wrong thing ... and here is the proof*" (Interviewee 5).

Outcomes: Benefits

Four benefits of recording encounters were described. The prime benefit was one of empowerment. As one patient said: "*In this context, it shifts the power dynamics. It doesn't revolutionize them, but it makes us less passive*" (Interviewee 5). Reflecting on the benefit, a patient said, "*In the NHS, I felt I had no power. So I just wanted to level the playing field a bit"* (Interviewee 7). Having a record of the encounter enhanced its value, and served multiple purposes. This benefit occurs whether the recording is undertaken covertly or with permission. However, three of the benefits were predicated on the recording being conducted overtly, with the explicit permission of the clinician. Recording, openly, was viewed as a mechanism to focus the clinician's attention, to reduce the power imbalance and potentially reduce future needs: "*I think it's just so important because it doubles or triples the value. Why wouldn't you do it?*" (Interviewee 5). Patients also noted that the process enhanced their ability to check whether they had explained themselves well, to "*actually listen to what I said*" (Interviewee 17).

Outcomes: Concerns

Multiple concerns were voiced about the act of recording clinical encounters. Some patients were worried about the new burden of owning such data, of having to listen and make sense of the new form of information "*... but, of course that depends on you being able to pick out ... the crucial points, ... pick them out and talk about them*" (Interview 11). In addition, given that the behavior is not only novel, it also cuts across the established etiquette of the patient-clinician interactions, and in part questions the established status of the professional as the one who legitimately documents the interaction. There is therefore a clear challenge to status, and this in turn, leads to patients reporting concern about damaging existing, or potential, professional relationships, or to be denied access to care by a clinician who has been angered by the process. One patient worried "*...that* [the doctor] *wasn't being as open and honest, that he would give me a different sort of care, because he would be worried that I was trying to catch him out*" (Interviewee 12). Concerns were also raised about the potential use of recordings for entrapment, for litigation against the clinician, as well as the possible loss of control of the recordings, and concerns about confidentiality and privacy.

Normalisation

As the interview data made clear, recording was viewed as a threat to established norms, and despite the willingness of some patients to seek permission, it was viewed as a request that would be viewed negatively by most clinicians. The suggested solution, widely made, was for "*people to do this routinely*" (Interviewee 9), i.e. to normalize the process and develop a policy where recording would not only be encouraged, it would be facilitated by the clinic. As one interview said: "*Maybe they are slowly coming to the realization that there ought to be nothing wrong with this*" (Interviewee 8). This strategy was viewed as a way to alleviate most, if not all the concerns, and to enable the benefits: "*if a sound recording was made just as a matter of routine ... They'd just be so used to it; it would just be a normal part of their day*" (Interviewee 14).

Many interviewees contrasted recording with written summaries of the encounter, made by the clinician or by the patient. Some preferred summaries, feeling that they were less burdensome. Others highlighted challenges, such as concerns about the accuracy of summaries and the disruption of trying to *"keep up*" (Interviewee 5), and difficult to catch "*new long words ...*" (Interview 17).

Discussion

Principal findings The portability and multiple capabilities of smartphones, or similar digital devices, has conferred increasing agency on some patients, who have decided to seek a more tangible record of their health care encounters. This is supported by the finding that 19 (15%) of our survey respondents indicated that they have secretly recorded a medical encounter, while 89 (69%) respondents indicated their *desire* to record clinical encounters, split equally between want to do so covertly or with permission. The overarching motivations to record resided in the ability to re-listen to the medical encounter on their own, or with others, to enhance recall and understanding of health information. Some patients were motivated by viewing recording as a potential means of obtaining verifiable evidence of poor care experienced.

We identified a subset of motivations that influenced the patient's decision to record either covertly or with permission. The decision to covertly record was associated with a fear of being denied permission to record, or where patients had prior experiences of poor quality care: the prospect of having verifiable evidence. Whereas, recording with permission was associated with a desire to maintain, even enhance, the relationship and trust between clinician and patient.

Our analysis tentatively suggests that individuals with less education were more likely to record covertly, indicative perhaps of a perceived stigma or disempowerment. Some patients were fearful that seeking permission would be counterproductive, concerned that permission would be denied and the relationship damaged, perhaps beyond repair. These patients, who were a minority viewpoint in the sample surveyed and interviewed, were prepared to record covertly.

Generally, patients cited many benefits, with the underpinning rationale that recording the encounter was a clear signal of empowerment, enhancing the value of the encounter, especially when permission was sought, thereby ensuring that clinicians were made aware of the process. There were also concerns: patients worried that recording might disturb established norms, and be at odds with the expected etiquette of being subservient and passive. On the professional side, there were concerns that recordings could provide data for possible litigation. To alleviate these concerns, many suggested that the process of recording clinical encounters should be normalized and become part of routine practice.

Weaknesses and strengths The survey we conducted was not representative of the UK population: 87% had a college education or higher, and were recruited from a radio audience or from social media. Respondents represent those who wanted to voice their opinion on this subject. Yet, we were able to gather a range of responses to the idea of recording clinical encounters, with and without permission. Examining this issue in more depth by combining a survey and interviews enabled us to examine motivations, uses, concerns and benefits, and to uncover multiple perspectives.

Results in context Our search for similar work did not yield comparative empirical studies. Related work that has evaluated *clinicians'* giving recordings to patients has consistently reported the benefits of increased understanding and better recall [3]. We identified the potential to use recordings as an adjunct to therapy, supporting findings from a previous study from a mental health setting [6]. Our analysis revealed the range of *patient* motivations to record as well as novel uses for the recordings. Our research group has analysed reactions of patients and clinicians posted in online media, concluding that the issue generates conflicting views about the legitimacy of the behavior, especially about covert recording [7]**.** We recognize the work in sociology that has drawn attention to power imbalance in clinical encounters [12]**,** and debates about patient-provider asymmetries [13]. The recent interest in shared decision making and patient involvement has led to efforts to modify this asymmetry, and to intervene, e.g. with information tools called patient decision aids [14], or use of patient activation tools [15]. These studies have documented effects but real-world implementation is an uphill effort. Recently, other efforts to increase transparency have been initiated, such as the Open Notes, giving patients the ability to comment on their records, with positive benefits reported [16]. Having access to a digital copy of the encounter could be the next step.

Implications Patients recording encounters does not seem to be a widespread phenomenon but this data, albeit it from an educated sample of people, does indicate that many patients seem in favour of having access to recordings, at least for some situations. Evidence that some organizations have recognised this comes from examples as the Oliver Cancer Center in the USA [17] giving recorders to patients, and making this the new 'normal'. Software

designed to support the recording of clinical encounters is beginning to emerge. There will be concerns about data security and ownership and so more guidance will be required. It is noteworthy for instance that the Care Quality Commission in the UK has published guidance about the use of hidden cameras [8].

Unanswered questions Conducting a larger more representative survey would provide more precise information about patient recording, but it is likely that such a snapshot would be transient, and would not add much more to an understanding of motivations and utility. The unanswered question is one about how organisations and clinicians at large will react to the concept of recording becoming normalized. Do recordings of the clinical encounter become part of the clinical record? And if so, what are the ramifications of how such data could be used and accessed?

Acknowledgements:

Contributions: Stuart Grande conducted the qualitative interviews, contributed to data interpretation and manuscript preparation. Paul Barr contributed to the study design, quantitative and qualitative analysis, and preparation of the manuscript. Glyn Elwyn initiated the study, participated in data analysis and prepared the article. He is the guarantor for the study.

All authors, external and internal, had full access to the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Transparency declaration: the lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained**.**

Ethical Approval: Ethical review of the study was conducted by the Center for Protection of Human Subjects, Dartmouth College, CPHS# STUDY00028222.

Funding sources: This study received no external funding.

Data sharing statement: Consent was not sought from participants to share study data. However interested parties should contact study authors to discuss access to de-identified data.

References

1 Elwyn G. 'Patientgate'-digital recordings change everything. *BMJ* 2014;**2078**:10–1.

2 Strong P. *The Ceremonial Order of the Clinic*. London: : Routledge 1979.

3 Tsulukidze M, Durand M-A, Barr PJ, *et al.* Providing recording of clinical consultation to patients - a highly valued but underutilized intervention: a scoping review. *Patient Educ Couns* 2014;**95**:297–304.

4 Good DW, Delaney H, Laird A, *et al.* Consultation audio-recording reduces long-term decision regret after prostate cancer treatment: A non-randomised comparative cohort study. *Surgeon* Published Online First: 27 January 2015. doi:10.1016/j.surge.2014.10.006

5 Santo A, Laizner AM, Shohet L. Exploring the value of audiotapes for health literacy: a systematic review. *Patient Educ Couns* 2005;**58**:235–43.

6 Shepherd L, Salkovskis PM, Morris M, *et al.* Recording therapy sessions: An evaluation of patient and therapist reported behaviours, attitudes and preferences. *Behav Cogn Psychother* 2009;**37**:141–50.

7 Tsulukidze M, Grande S, Thompson R, *et al.* Patients covertly recording clinical encounters: threat or opportunity? A qualitative analysis of online text. *PLoS One* 2015;**In Press**.

8 Care Quality Commission. Thinking about using a hidden camera or other equipment to monitor someone's care? London: 2015. http://www.cqc.org.uk/sites/default/files/20150212_public_surveillance_leaflet_final.pdf (accessed 14 Mar2015).

9 Elwyn G, Buckman L. Should doctors encourage patients to record consultations? *BMJ* 2015;**350**:g7645.

10 Miles M, Huberman A. *Qualitative data analysis: An expanded sourcebook*. San Francisco: : SAGE publications, Inc 1994.

11 O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010;**341**:c4587.

12 Szasz T, Hollender M. A contribution to the philosophy of medicine: the basic models of of the doctor-patient relationship. *Arch Intern Med* 1956;**97**:585–92.

13 Maseide P. Possibly abusive, often benign, and always necessary. On power and domination in medical practice. *Sociol Heal Illn* 1991;**13**:545–61.

14 Stacey D, Légaré F, Col NF, *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane database Syst Rev* 2014;**1**:CD001431.

15 Kinnersley P, Edwards A, Hood K, *et al.* Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. *BMJ* 2008;**337**:a485–a485.

16 Delbanco T, Walker J, Bell SK, *et al.* Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Ann Intern Med* 2012;**157**:461–70.

17 Oliver Cancer Center. Patient Visit Recording Project: Taking the Message and Medicine Home. http://www.utmb.edu/olivercenter/projects/current/pvr_1.asp (accessed 14 Mar2015).

Table 1 **Respondent characteristics (n = 130)**

Survey item	Respondent totals, N
Gender	
Male Female Other	55 (44%) 70 (56%) 1 (1%)
Age	
18 – 40	53 (41%)
41- 60	54 (42%)
>60	23 (18%)
Education	
One or more GCSEs or O-Levels	5 (4%)
Apprenticeship or other related qualification	4 (3%)
One or more A-levels	6 (5%)
Degree or higher professional qualification	110 (87%)
Left school with no formal qualifications	2 (2%)
Country of residence	
England	86 (67%)
Northern Ireland	8 (6%)
Scotland	3 (2%)
Wales	7 (6%)
Other	24 (19%)
Language spoken, other than English, at home?	
Yes	20 (16%)

Table 2 Experience and views on patients secretly recording encounters

	Respondent totals, N
Have you ever secretly recorded a visit to a doctor or another medical professional?	
Yes	19 (15%)
No, but I know some who has	14 (11%)
No, and I do not know anyone who has	95 (74%)
Would you consider secretly recording a visit to a doctor or another health professional?	
Yes, I would consider secretly recording a visit	45 (35%)
No, but I would consider recording a visit after asking permission	44 (34%)
No, I have no interest in recording a visit	39 (31%)
Would you like your clinic to allow you to record visits with a doctor or another health professional?	
Yes	98 (77%)
No	29 (23%)

Appendix 1 Interview schedule

Thank you for agreeing to be interviewed for this study. In order to make sure you understand the purpose of this research, we are going to be asking you questions today based on the idea that you have either used a recording device to record a clinical visit with your physician, therapist, nurse, or health provider or plan to use one in the future.

Over the next 15-20 minutes I will be asking you several open-ended questions related to your experiences recording a clinical visit. You may stop at any time, without consequence. The information you share will remain anonymous and will be accessible only to members of our research team. Before we begin, do you have any questions for me?

Patients who have recorded covertly

1) Please the time when you recorded a clinical visit
2) Talk a bit more about what lead you to record that visit
3) Before recording your visit, did you seek permission from anyone at the clinic or from your (physician, nurse, therapist, etc.)? If yes/no, who did you ask and what was their reaction?
4) How did your (physician, nurse, therapist, etc.) react to your recording
5) In what way has this recording helped or hindered your experience as a patient.
6) In your opinion, how might recording visits be useful or beneficial for patients?
7) What might be some perceived challenges to recording a clinical visit? How have you overcome these challenges or seen past them?
8) You are one of seven participants who agreed to be interviewed and one of 19 respondents who said they had covertly recorded their clinical encounter. What do you think kept those other 12 respondents from agreeing to be interviewed? Is there something about those who covertly record from those who don't?

Patients who would record covertly

1) Please tell me more about why you would choose to record a clinical visit
2) What might some reasons be for not asking permission from your doctor
3) In your mind, what might be the benefits of recording a clinical encounter?
4) If you were to record your clinician, how might you do it?
5) What might be some fears patients have about recording?
6) How might the act of recording benefit you as a patient, and how do you think your provider might react
7) You are one of 26 participants who agreed to be interviewed and one of 45 respondents who said they would covertly recorded their clinical encounter. What do you think kept those others from agreeing to be interviewed? What are potential differences among those who covertly record from those who don't?

Patients who would record openly

1) Please tell me more about why you would choose to record a clinical visit
2) What might some reasons be for not asking permission from your doctor
3) In your mind, what might be the benefits of recording a clinical encounter?
4) If you were to record your clinician, how might you do it?
5) What might be some fears patients have about recording?
6) How might the act of recording benefit you as a patient, and how do you think your provider might react
7) You are one of 21 participants who agreed to be interviewed from a total of 43 respondents who said they would openly recorded their clinical encounter. What do you think kept those others from agreeing

to be interviewed? What are potential differences among those who might openly record from those who might covertly record?

Patients who would not record

1) Can you talk about why you choose not to record your clinical visit?
2) Describe a situation where a clinical recording might or might not be useful?
3) I'd like you to explain what the patient provider relationship means to you.
4) What might be some fears patients have about recording?
5) How might a provider react to a patient recording their visit? Would this change if the provider was asked ahead of time?
6) You are one of 10 participants who agreed to be interviewed from a total of 38 respondents who said they would not record their clinical encounter. What do you think kept those others from agreeing to be interviewed? What are potential differences among those who might record from those who wouldn't?

Appendix 2 **Details of interviewees included in this study, by category (n=17)**

Demographics	Would ask permission (n=7)	Would secretly record (n=5)	Would not secretly record (n=2)	Have recorded secretly (n=3)
Gender				
Male	0	3	1	3
Female	7	2	1	0
Other	0	0	0	0
Age				
18-40	1	1	0	1
41-60	3	4	1	1
>60	1	0	1	1
Education				
Degree or higher professional qualification	7	5	2	3
Language other than English spoken at home				
Yes	1	0	0	0
No	6	5	2	3

A competing interest declaration.

This should be composed after each author has filled in the International Committee of Medical Journal Editors' Unified Competing Interest form and the corresponding author should keep the completed forms in case they are required later. Please then add to the manuscript a statement in the following format: All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) [initials of relevant authors] have support from [name of company] for the submitted work; (2) [initials of relevant authors] have [no or specified] relationships with [name of companies] that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have [specified] financial relationships that may be relevant to the submitted work; and (4) [initials of relevant authors] have no [or specified] non-financial interests that may be relevant to the submitted work."

License

BMJ Open

Patients' recording clinical encounters: A path to empowerment? Assessment by mixed methods.

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2015-008566.R1
Article Type:	Research
Date Submitted by the Author:	29-Jun-2015
Complete List of Authors:	Elwyn, Glyn; The Dartmouth Institute for Clinical Practice and Health Policy, Barr, Paul; The Dartmouth Institute for Clinical Practice and Health Policy, Grande, Stuart; The Dartmouth Institute for Clinical Practice and Health Policy,
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Evidence based practice, Health services research, Health policy, Patient-centred medicine
Keywords:	MEDICAL ETHICS, MEDICAL LAW, QUALITATIVE RESEARCH

Patients' recording clinical encounters: A path to empowerment? Assessment by mixed methods.

Glyn Elwyn, Paul James Barr, Stuart W Grande

The Preference Laboratory
The Dartmouth Institute for Health Policy and Clinical Practice
Dartmouth College
Hanover
New Hampshire USA 03755
Glyn Elwyn, professor
Paul Barr, assistant professor
Stuart W Grande, postdoctoral researcher

Corresponding author: Glyn Elwyn glynelwyn@gmail.com

The Dartmouth Institute for Health Policy and Clinical Practice
Dartmouth College
Hanover
New Hampshire USA 03755

Word count – excluding tables / figure 4213

Abstract (300 words)

Objective To examine the motivations of patients recording clinical encounters, covertly or otherwise, and why some do not wish to record encounters.

Design Mixed methods analysis of survey data and nested semi-structured interviews.

Setting Survey to UK audience, using social media and radio broadcast.

Participants 168 survey respondents, aged 18 years or older, of which 161 were 18 years of age or older (130 completions). Of the 56 participants who agreed to be contacted, we included data from 17 interviews.

Results Nineteen (15%) respondents indicated having secretly recorded a clinical encounter and 14 (11%) were aware of someone who had secretly recorded a clinical encounter. Forty five (35%) said they would consider recording secretly, and 44 (34%) would do so after asking permission. A total of 69% of respondents indicated their *desire* to record clinical encounters, split equally between wanting to do so covertly or with permission. Thematic analysis of the interviews showed that most patients are motivated by the wish to replay, re-listen and share the recording with others. Some are also motivated by the idea of owning a personal record, and its potential use as verification of a poor healthcare experience. The rationale for permission-seeking was based on the wish to prioritise a trusting relationship with a health professional. Those who preferred to record covertly described a pre-existing lack of trust, a fear that recording would be denied, and a concern that an affronted clinician would deny them access to future care. There was a general wish that recording should be facilitated.

Conclusions Patients' prime motivation for recording is to enhance their experience of care, and to share it with others. Patients know that recording challenges the "ceremonial order of the clinic", and so some decide to act covertly. Patients wanted clearer, more permissive policies to be developed.

Strengths and limitations of this study

- This study is the first to estimate the extent to which patient recording of medical encounters, covert or open, is occurring in the UK and motivations to do so.
- The mixed methods design is a strength of this project
- A convenience sample was used, which limits the generalizability of the results
- Themes derived from patient interviews were triangulated with open comments made on the survey

Introduction

Mobile technology has become pervasive; it is no surprise that it has found its way into medical encounters, with reports of patients recording clinical encounters using either smartphones, or other devices. Some ask permission and others do it covertly [1]. The behavior is new, facilitated by devices that make this easy. It may also indicate the development of a new attitude towards what has been called the 'ceremonial order of the clinic'[2], challenging the established etiquette of a deferential and subservient patient norm.

There are studies of clinicians deciding to offer recordings to patients, particularly in paediatrics and in oncology, where complex, emotional subjects are discussed, and information given which is especially difficult to retain. A recent review showed that patients valued the ability to re-listen to the recordings, often doing so more than once, as well as being able to share recordings with their family [3]. Patient's recall is clearly enhanced by having access to recordings [3]. A more recent study also found statistically significant reductions in decisional regret for patients with access to recordings [4]**.** These benefits could be of value to patients, particularly to those with low literacy, although there is a lack of research on this issue [3][5]. In mental health and family medicine settings, recordings have been used for clinical training. Where recordings have been shared with patients, their use as adjuncts to therapy has been reported [6].

Despite the documented benefits associated with clinicians offering recordings to patients, routine recording of clinical encounters is uncommon. Now patients are deciding to record encounters themselves, some doing so covertly [7]. Clinicians are becoming aware of the possibility of being recorded and are concerned that the recordings, especially those that are covert, would be used for litigation purposes [7]. Policy makers have begun, for the first time, to provide guidance to patients who are considering covert recording [8].

Although the topic of covert recording has been the subject of recent debate [1][9], we could find no research that has investigated the phenomenon of patients deciding to record their own clinical encounters. The aim of this study was to explore this behaviour, to estimate to what extent it is occurring or is desired, and to understand more about why individuals are motivated to record and how they navigate the decision to do so by seeking permission or by acting covertly.

Method

Survey design and participants

We administered a cross-sectional survey online, after an interview broadcast on BBC Radio 4 (July 8th, 2014). In the program, one of the study authors (GE) talked about the pros and cons of patients recording their clinical encounters. The opportunity to complete a survey about this topic was announced and advertised on the programme website, and through social media. Respondents, over the age of 18, were asked three closed-response questions about their experience and views of recording encounters with a health professional: 1) Have you ever secretly recorded your encounter with a health professional? 2) Would you consider secretly recording your encounter? 3) Would you like your clinic to allow you to record your encounters? We included questions about age, gender, education, country of residence, and whether English was the only language spoken at home and space was given for further comments.

Quantitative Data Analysis

Categorical responses of respondents from the UK were summarized. Where appropriate, Pearson's chi-square test of independence was used to identify statistical association between categorical variables. Where cell counts were under five, we used Fisher's exact tests. Hypothesis generating multiple logistic regression analyses were conducted to explore respondent characteristics associated with the act of covert recording, compared to all other respondents. We also conducted an analysis comparing the characteristics of individuals who would record a medical encounter with permission to those who would covertly record. All analyses were adjusted for age, gender, language spoken at home and education. Analyses were conducted using STATA, Version 13.0, StataCorp, College Station, Texas.

Qualitative interviews

We contacted respondents who had provided an email address in the survey and conducted semi-structured interviews with consenting participants using an agreed schedule (Appendix 1). We purposefully sampled

respondents based upon survey responses: 1) have covertly record; 2) would covertly record; 3) would only record with clinician's permission; and 4) have no interest in recording.

We developed the interview schedule *a priori,* making modifications based on the respondents' experience of covert recording, or willingness to record, covertly, with permission or not at all. The interview covered the following topics: experience of recording or willingness to record, and their motivations do so covertly, with permission or not at all; perceived benefits and possible negative consequences of recording, both overt and covert, and the consequences and experiences of requesting permission to record. Attention was given to the issues raised at preceding interviews, enabling further probing into salient topics and concerns, consistent with a grounded theory approach. All interviews were conducted over the telephone, recorded and transcribed.

Data Analysis

Before embarking on qualitative analysis of the interview transcripts, two researchers met (SG and PB) and developed an initial codebook, based on the interview questions [10]. This process informed a thematic analysis of interview transcripts where initial codes are grouped by salient themes. Independent coding was completed with the initial codebook. Emergent codes were added, and existing codes revised where necessary. PB & SG met to discuss and assess potential additions to the codebook; disagreements were discussed and resolved. A second coding process was undertaken to apply the revised codebook to the data. Codes, memos, short narrative summations of data, were entered into a spreadsheet for further discussion with a member of the research team who had also read the transcripts (GE). By critically reviewing the codes and associated memos, the data were categorized using a conceptual mapping process [10]. We checked the categorization by comparing the open-text survey comments to the interview data [11].

Results

A total of 168 individuals responded to the survey. Seven were under 18 years old, and therefore ineligible. Of the 161 eligible respondents, 130 completed the survey. There were no significant differences in gender, age or educational attainment between individuals who completed the survey and those who did not. A description of respondent characteristics can be found in Table 1.

Do people secretly record their medical encounters?

Of the 130 complete respondents, 128 answered the questions regarding their experience and views on covertly recording a visit with a health professional (Table 2). In this sample, covert recording had been performed, or known about, by 33 (26%) respondents. A total of 19 (15%) respondents reported secretly recording a medical encounter, with a further 14 (11%) respondents, reporting that they personally know of someone who has secretly recorded an encounter. When asked if they would consider recording a medical a visit with a health professional, 45 (35%) respondents stated that they would, and a further 44 (34%) indicated a willingness to record only after asking the clinician for permission. Finally, 98 (77%) respondents indicated that they would like their clinic to allow recordings of medical encounters.

Recording covertly or with permission.

Multiple logistic regression analysis indicated that among respondents, individuals who reported making a covert recording were more likely to be male, OR 3.6 (95% CI 1.16 to 11; P=0.03) and have less than a university education, OR 5.5 times (95% CI 1.35 to 22.4; P=0.02). A second analysis indicated that individuals who would only record with permission from the clinician, compared to those who would covertly record, were more likely to have a university education, OR 11.1 (95% CI 2.1 to 60.6; P=0.004).

Qualitative Analysis

Out of the 130 respondents who completed the survey 56 agreed to be contacted. Of those 56, 21 consented, and 18 were interviewed. We excluded data from one respondent who was not from the UK. We included data from 17 interviews, 10 women and 7 men, all of whom had college (or higher) levels of education; 70% were 41 years or older, and all spoke English at home, save for one individual (for details, see Appendix 2). Three of the interviewees had covertly recorded in the past, five interviewees would consider secretly recording, seven interviewees would only record with permission, and two interviewees would not record. Figure 1 provides a thematic representation of the interview data.

It was evident that the availability of digital technology had to a large extent facilitated patients to consider recording clinical encounters, as one individual said: *"we've all got devices that are portable and easy to record with"* (Interviewee 1). Although not all patients will want to make use of the capability, smartphones and other devices can be used with minimal disruption, making covert recording possible. Patients described their motivations to record, and their rationale for either asking permission or acting covertly. They also described how they made use of such recordings, including the associated benefits and concerns. A recurring concern was that recording would violate the etiquette expected in clinical encounters, a deviation from the passive role of the patient. Consequently, many patients volunteered that the solution to this tension would be to 'normalise' the behaviour, to make it part of usual practice. After the interview data were analysed, we compared our findings to the 76 open-text comments in the survey, and found no new themes.

< Insert Figure 1> Thematic data representation

Motivations to record

We ascertained five prominent reasons that motivated patients to record clinical encounters. The chief motivation for patients to record was the desire to enhance their understanding of the encounter, and in addition, to share their experience of the encounter with others, particularly when the problems and treatments were complex. There was one instance of a patient describing a therapeutic motivation, where re-listening to the encounter was viewed as an additional and complementary therapeutic input. The less explicitly stated motivation was to have a sense of data ownership, that the experience was somehow more tangible by being on record, acting essentially as a *"backup for my brain"* (Interviewee 17), and was in their possession: *"So my real motivation for doing the recordings was so that I had a record of what they were actually doing, what they were saying"* (Interviewee 7). In some instances, this sense of ownership was motivated by prior negative experiences, and the wish to have verifiable evidence of such an experience, should it recur.

Once a patient has decided to record an encounter, they come to a crossroads, should I record covertly or with permission?

Rationale for covert recording

Decisions to record covertly were based on concerns about negative consequences. Interviewees, keen to obtain a recording, had considered asking for permission yet had acted covertly due to a fear of being denied permission. Interviewees felt it was easier *"to apologize later"* rather than *"deal with the refusal"* (Interviewee 14). A interviewee who was also a clinician, also acknowledged this fear: "*I think it's quite possible that my clients might have recorded something, an interview with me, without telling me, possibly if they thought I might say no*" (Interviewee 2).

Fear of denial was related to the worry that clinicians would be affronted by requests to record, to the point of asking patients to leave their care, a particular concern for those living in rural areas with limited options. One interviewee started out recording with permission, but after "*being threatened with removal from the practice*" (Interviewee 8) began to record covertly.

Another factor leading to covert recording was experiencing *"jaw-droppingly awful treatment"* (Interviewee 8), and wanting to have evidence of such an event. Interviewees felt that without such evidence, it was a situation of "*his word versus yours"* (Interviewee 9), and as "*the doctor can never be wrong"* (Interviewee 9), it was necessary to have "*actual tape recorded evidence... to protect yourself* [the patient]*"* (Interviewee 17).

One interviewee mentioned their experience of using the recording as evidence of bad care and said that it had led improvement in the quality of their next encounters: "*[I] put in the complaint, [and] that I [the patient] have a tape recording of the conversation*". When asked about the clinic's reaction, the interviewee stated that "*no mention was made* [to the recording] *in the reply",* and since the complaint had been placed, that their "*treatment there has been exemplary"* (Interviewee 14).

Rationale for asking permission

The majority of interviewees indicated a desire to record with permission. Maintaining and protecting the relationship with their clinician was a priority: "*It's a real partnership thing, isn't it?"* (Interviewee 16). They feared that covertly recording an encounter "*would be a breach of trust*" (Interviewee 12) between the patient and clinician, and that as a patient, "*you owe the clinician an explanation*" (Interviewee 13) for wanting to record. Interviewees felt like recording and "*not asking permission would be like subterfuge*" (Interviewee 1). One interviewee who been covertly recording indicated their discomfort and regret of recording without permission, to the extent that they were considering changing their stance.

Several interviewees felt that obtaining permission would have more impact, and lead to greater benefits, "*... because as I say, the physician would know that there was accountability*" (Interviewee 17). Whereas, "*If you do it covertly, they [the clinicians] wouldn't know would they, so I don't think it would change what was said in the room"* (Interviewee 6). Acting covertly would they argued lead to only "*getting half of the benefit out of the recording*" (Interviewee 8). Requesting permission was also viewed as a means of increasing mutual respect: "*I think if it was done openly, and with agreement to both parties, I think it could help develop more trust in the relationship*" (Interviewee 12). In addition, on a purely practical level, gaining permission enables a device to be used openly, facilitating a "*... better quality recording*" (Interviewee 14).

Use of recording

Those interviewed described four distinct uses of the recordings. Re-listening was the prime use, "*... to help me better understand what they said, because sometimes they talk so quickly"* (Interviewee 15*).* The ability to share the recording with others was very important to many individuals. One mentioned that the recording could be used for therapeutic purposes, particularly if the clinician was prepared to collaborate and support such a goal. The recording could also be used as proof of care received, with the clear implication that such data could constitute evidence of unsatisfactory care, should such a situation occur.

To re-listen to information exchanged

Interviewees who found it difficult to recall clinical encounters, were often unable to follow what was said, either because it was unclear, or delivered too quickly. It was widely felt that even though a patient might refer "*back to it* [the recording] *once or twice...* [many] *just found it useful to have as a reference*" (Interviewee 7)

Share with others

A common frustration reported by patients was an inability to give a good account of their clinical encounter. Interviewees acknowledged the significant benefit of: "*... bringing people into the process*" (Interview 4) by replaying the recording. This was viewed as a more reliable way of ensuring that others were able to understand the advice given, and as help to "*follow whatever instructions were provided*" (Interviewee 13).

For therapeutic purposes

An unexpected use of a recording was to revisit "*the emotion of the conversation*", to re-listen to the "*tone of voice*" to "*get all that reassurance and attachment stuff*" (Interviewee 5). This therapeutic use of the recording was made possible by the ability to replay the encounter: *"... when I listen back, I feel very supported and validated by those little things which I've missed first time round ... that sorts of reinforces the benefits of the therapy*" (Interviewee 5).

Proof of care received

The interviews indicated there was a desire by some to use the recordings as proof of interactions experienced. This was triggered by a sense that without having proof, concerns had too often been dismissed in the past: *"I think it could have helped to support my story of what happened"* (Interviewee 16). Patients reported the need to have verification, and that if they were unsatisfied, their word alone was insufficient: "*When you're experiencing poor engagement with your clinician ... it* [a recording] *would be really useful as a kind of evidence*" (Interviewee 6). A recording was viewed as less open to dispute: "*... he was being unsupportive, he said the wrong thing ... and here is the proof*" (Interviewee 5).

Outcomes: Benefits

Four benefits of recording encounters were described. The prime benefit was one of empowerment. As one patient said: "*In this context, it shifts the power dynamics. It doesn't revolutionize them, but it makes us less passive*" (Interviewee 5). Reflecting on the benefit, a patient said, "*In the NHS, I felt I had no power. So I just wanted to level*

the playing field a bit" (Interviewee 7). Having a record of the encounter enhanced its value, and served multiple purposes. This benefit occurs whether the recording is undertaken covertly or with permission. However, three of the benefits were predicated on the recording being conducted overtly, with the explicit permission of the clinician. Recording, openly, was viewed as a mechanism to focus the clinician's attention, to reduce the power imbalance and potentially reduce future needs: "*I think it's just so important because it doubles or triples the value. Why wouldn't you do it?*" (Interviewee 5). Patients also noted that the process enhanced their ability to check whether they had explained themselves well, to "*actually listen to what I said*" (Interviewee 17).

Outcomes: Concerns

Multiple concerns were voiced about the act of recording clinical encounters. Some patients were worried about the new burden of owning such data, of having to listen and make sense of the new form of information "*... but, of course that depends on you being able to pick out ... the crucial points, ... pick them out and talk about them*" (Interview 11). In addition, given that the behavior is not only novel, it also cuts across the established etiquette of the patient-clinician interactions, and in part questions the established status of the professional as the one who legitimately documents the interaction. There is therefore a clear challenge to status, and this in turn, leads to patients reporting concern about damaging existing, or potential, professional relationships, or to be denied access to care by a clinician who has been angered by the process. One patient worried "*...that* [the doctor] *wasn't being as open and honest, that he would give me a different sort of care, because he would be worried that I was trying to catch him out*" (Interviewee 12). Concerns were also raised about the potential use of recordings for entrapment, for litigation against the clinician, as well as the possible loss of control of the recordings, and concerns about confidentiality and privacy.

Normalisation

As the interview data made clear, recording was viewed as a threat to established norms, and despite the willingness of some patients to seek permission, it was viewed as a request that would be viewed negatively by most clinicians. The suggested solution, widely made, was for "*people to do this routinely*" (Interviewee 9), i.e. to normalize the process and develop a policy where recording would not only be encouraged, it would be facilitated by the clinic. As one interview said: "*Maybe they are slowly coming to the realization that there ought to be nothing wrong with this*" (Interviewee 8). This strategy was viewed as a way to alleviate most, if not all the concerns, and to enable the benefits: "*if a sound recording was made just as a matter of routine ... They'd just be so used to it; it would just be a normal part of their day*" (Interviewee 14).

Many interviewees contrasted recording with written summaries of the encounter, made by the clinician or by the patient. Some preferred summaries, feeling that they were less burdensome. Others highlighted challenges, such as concerns about the accuracy of summaries and the disruption of trying to *"keep up*" (Interviewee 5), and difficult to catch "*new long words ...*" (Interview 17).

Discussion

Principal findings The portability and multiple capabilities of smartphones, or similar digital devices, has conferred increasing agency on some patients, who have decided to seek a more tangible record of their health care encounters. This is supported by the finding that 19 (15%) of our survey respondents indicated that they have secretly recorded a medical encounter, while 89 (69%) respondents indicated their *desire* to record clinical encounters, split equally between want to do so covertly or with permission. The overarching motivations to record resided in the ability to re-listen to the medical encounter on their own, or with others, to enhance recall and understanding of health information. Some patients were motivated by viewing recording as a potential means of obtaining verifiable evidence of poor care experienced.

We identified a subset of motivations that influenced the patient's decision to record either covertly or with permission. The decision to covertly record was associated with a fear of being denied permission to record, or where patients had prior experiences of poor quality care: the prospect of having verifiable evidence. Whereas, recording with permission was associated with a desire to maintain, even enhance, the relationship and trust between clinician and patient.

Our analysis tentatively suggests that individuals with less education were more likely to record covertly, indicative perhaps of a perceived stigma or disempowerment. Some patients were fearful that seeking permission would be

counterproductive, concerned that permission would be denied and the relationship damaged, perhaps beyond repair. These patients, who were a minority viewpoint in the sample surveyed and interviewed, were prepared to record covertly.

Generally, patients cited many benefits, with the underpinning rationale that recording the encounter was a clear signal of empowerment, enhancing the value of the encounter, especially when permission was sought, thereby ensuring that clinicians were made aware of the process. There were also concerns: patients worried that recording might disturb established norms, and be at odds with the expected etiquette of being subservient and passive. On the professional side, there were concerns that recordings could provide data for possible litigation. To alleviate these concerns, many suggested that the process of recording clinical encounters should be normalized and become part of routine practice.

Weaknesses and strengths The survey we conducted was not representative of the UK population: 87% had a college education or higher, and were recruited from a radio audience or from social media. Respondents represent those who wanted to voice their opinion on this subject. Yet, we were able to gather a range of responses to the idea of recording clinical encounters, with and without permission. Examining this issue in more depth by combining a survey and interviews enabled us to examine motivations, uses, concerns and benefits, and to uncover multiple perspectives.

Results in context Our search for similar work did not yield comparative empirical studies. Related work that has evaluated *clinicians'* giving recordings to patients has consistently reported the benefits of increased understanding and better recall [3]. We identified the potential to use recordings as an adjunct to therapy, supporting findings from a previous study from a mental health setting [6]. Our analysis revealed the range of *patient* motivations to record as well as novel uses for the recordings. Our research group has analysed reactions of patients and clinicians posted in online media, concluding that the issue generates conflicting views about the legitimacy of the behavior, especially about covert recording [7]**.** We recognize the work in sociology that has drawn attention to power imbalance in clinical encounters [12]**,** and debates about patient-provider asymmetries [13]. The recent interest in shared decision making and patient involvement has led to efforts to modify this asymmetry, and to intervene, e.g. with information tools called patient decision aids [14], or use of patient activation tools [15]. These studies have documented effects but real-world implementation is an uphill effort. Recently, other efforts to increase transparency have been initiated, such as the Open Notes, giving patients the ability to comment on their records, with positive benefits reported [16]. Having access to a digital copy of the encounter could be the next step.

Implications Patients recording encounters does not seem to be a widespread phenomenon but this data, albeit it from an educated sample of people, does indicate that many patients seem in favour of having access to recordings, at least for some situations. Evidence that some organizations have recognised this comes from examples as the Oliver Cancer Center in the USA [17] giving recorders to patients, and making this the new 'normal'. Software designed to support the recording of clinical encounters is beginning to emerge. There will be concerns about data security and ownership and so more guidance will be required. It is noteworthy for instance that the Care Quality Commission in the UK has published guidance about the use of hidden cameras [8].

Unanswered questions Conducting a larger more representative survey would provide more precise information about patient recording, but it is likely that such a snapshot would be transient, and would not add much more to an understanding of motivations and utility. The unanswered question is one about how organisations and clinicians at large will react to the concept of recording becoming normalized. Do recordings of the clinical encounter become part of the clinical record? And if so, what are the ramifications of how such data could be used and accessed?

Acknowledgements:

Contributions: Stuart Grande conducted the qualitative interviews, contributed to data interpretation and manuscript preparation. Paul Barr contributed to the study design, quantitative and qualitative analysis, and preparation of the manuscript. Glyn Elwyn initiated the study, participated in data analysis and prepared the article. He is the guarantor for the study.

All authors, external and internal, had full access to the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Transparency declaration: the lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained**.**

Ethical Approval: Ethical review of the study was conducted by the Center for Protection of Human Subjects, Dartmouth College, CPHS# STUDY00028222.

Funding sources: This study received no external funding.

Data sharing statement: Consent was not sought from participants to share study data. However interested parties should contact study authors to discuss access to de-identified data.

References

1 Elwyn G. 'Patientgate'-digital recordings change everything. *BMJ* 2014;**2078**:10–1. doi:10.1136/bmj.g2078

2 Strong P. *The Ceremonial Order of the Clinic*. London: : Routledge 1979.

3 Tsulukidze M, Durand M-A, Barr PJ, *et al.* Providing recording of clinical consultation to patients - a highly valued but underutilized intervention: a scoping review. *Patient Educ Couns* 2014;**95**:297–304.

4 Good DW, Delaney H, Laird A, *et al.* Consultation audio-recording reduces long-term decision regret after prostate cancer treatment: A non-randomised comparative cohort study. *Surgeon* Published Online First: 27 January 2015. doi:10.1016/j.surge.2014.10.006

5 Santo A, Laizner AM, Shohet L. Exploring the value of audiotapes for health literacy: a systematic review. *Patient Educ Couns* 2005;**58**:235–43. doi:10.1016/j.pec.2004.07.001

6 Shepherd L, Salkovskis PM, Morris M, *et al.* Recording therapy sessions: An evaluation of patient and therapist reported behaviours, attitudes and preferences. *Behav Cogn Psychother* 2009;**37**:141–50. doi:10.1017/S1352465809005190

7 Tsulukidze M, Grande S, Thompson R, *et al.* Patients covertly recording clinical encounters: threat or opportunity? A qualitative analysis of online text. *PLoS One* 2015;**In Press**.

8 Care Quality Commission. Thinking about using a hidden camera or other equipment to monitor someone's care? London: 2015. http://www.cqc.org.uk/sites/default/files/20150212_public_surveillance_leaflet_final.pdf (accessed 14 Mar2015).

9 Elwyn G, Buckman L. Should doctors encourage patients to record consultations? *BMJ* 2015;**350**:g7645.

10 Miles M, Huberman A. *Qualitative data analysis: An expanded sourcebook*. San Francisco: : SAGE publications, Inc 1994.

11 O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010;**341**:c4587. doi:10.1136/bmj.c4587

12 Szasz T, Hollender M. A contribution to the philosophy of medicine: the basic models of of the doctor-patient relationship. *Arch Intern Med* 1956;**97**:585–92.

13 Maseide P. Possibly abusive, often benign, and always necessary. On power and domination in medical practice. *Sociol Heal Illn* 1991;**13**:545–61. doi:10.1111/1467-9566.ep10843655

14 Stacey D, Légaré F, Col NF, *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane database Syst Rev* 2014;**1**:CD001431. doi:10.1002/14651858.CD001431.pub4

15 Kinnersley P, Edwards A, Hood K, *et al.* Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. *BMJ* 2008;**337**:a485–a485. doi:10.1136/bmj.a485

16 Delbanco T, Walker J, Bell SK, *et al.* Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Ann Intern Med* 2012;**157**:461–70. doi:10.7326/0003-4819-157-7-201210020-00002

17 Oliver Cancer Center. Patient Visit Recording Project: Taking the Message and Medicine Home. http://www.utmb.edu/olivercenter/projects/current/pvr_1.asp (accessed 14 Mar2015).

Table 1 **Respondent characteristics (n = 130)**

Survey item	Respondent totals, N
Gender	
Male Female Other	55 (44%) 70 (56%) 1 (1%)
Age	
18 – 40	53 (41%)
41- 60	54 (42%)
>60	23 (18%)
Education	
One or more GCSEs or O-Levels	5 (4%)
Apprenticeship or other related qualification	4 (3%)
One or more A-levels	6 (5%)
Degree or higher professional qualification	110 (87%)
Left school with no formal qualifications	2 (2%)
Country of residence	
England	86 (67%)
Northern Ireland	8 (6%)
Scotland	3 (2%)
Wales	7 (6%)
Other	24 (19%)
Language spoken, other than English, at home?	
Yes	20 (16%)

Table 2 Experience and views on patients secretly recording encounters

	Respondent totals, N
Have you ever secretly recorded a visit to a doctor or another medical professional?	
Yes	19 (15%)
No, but I know some who has	14 (11%)
No, and I do not know anyone who has	95 (74%)
Would you consider secretly recording a visit to a doctor or another health professional?	
Yes, I would consider secretly recording a visit	45 (35%)
No, but I would consider recording a visit after asking permission	44 (34%)
No, I have no interest in recording a visit	39 (31%)
Would you like your clinic to allow you to record visits with a doctor or another health professional?	
Yes	98 (77%)
No	29 (23%)

Appendix 1 Interview schedule

Thank you for agreeing to be interviewed for this study. In order to make sure you understand the purpose of this research, we are going to be asking you questions today based on the idea that you have either used a recording device to record a clinical visit with your physician, therapist, nurse, or health provider or plan to use one in the future.

Over the next 15-20 minutes I will be asking you several open-ended questions related to your experiences recording a clinical visit. You may stop at any time, without consequence. The information you share will remain anonymous and will be accessible only to members of our research team. Before we begin, do you have any questions for me?

Patients who have recorded covertly

1) Please the time when you recorded a clinical visit
2) Talk a bit more about what lead you to record that visit
3) Before recording your visit, did you seek permission from anyone at the clinic or from your (physician, nurse, therapist, etc.)? If yes/no, who did you ask and what was their reaction?
4) How did your (physician, nurse, therapist, etc.) react to your recording
5) In what way has this recording helped or hindered your experience as a patient.
6) In your opinion, how might recording visits be useful or beneficial for patients?
7) What might be some perceived challenges to recording a clinical visit? How have you overcome these challenges or seen past them?
8) You are one of seven participants who agreed to be interviewed and one of 19 respondents who said they had covertly recorded their clinical encounter. What do you think kept those other 12 respondents from agreeing to be interviewed? Is there something about those who covertly record from those who don't?

Patients who would record covertly

1) Please tell me more about why you would choose to record a clinical visit
2) What might some reasons be for not asking permission from your doctor
3) In your mind, what might be the benefits of recording a clinical encounter?
4) If you were to record your clinician, how might you do it?
5) What might be some fears patients have about recording?
6) How might the act of recording benefit you as a patient, and how do you think your provider might react
7) You are one of 26 participants who agreed to be interviewed and one of 45 respondents who said they would covertly recorded their clinical encounter. What do you think kept those others from agreeing to be interviewed? What are potential differences among those who covertly record from those who don't?

Patients who would record openly

1) Please tell me more about why you would choose to record a clinical visit
2) What might some reasons be for not asking permission from your doctor
3) In your mind, what might be the benefits of recording a clinical encounter?
4) If you were to record your clinician, how might you do it?
5) What might be some fears patients have about recording?
6) How might the act of recording benefit you as a patient, and how do you think your provider might react
7) You are one of 21 participants who agreed to be interviewed from a total of 43 respondents who said they would openly recorded their clinical encounter. What do you think kept those others from agreeing

to be interviewed? What are potential differences among those who might openly record from those who might covertly record?

Patients who would not record

1) Can you talk about why you choose not to record your clinical visit?
2) Describe a situation where a clinical recording might or might not be useful?
3) I'd like you to explain what the patient provider relationship means to you.
4) What might be some fears patients have about recording?
5) How might a provider react to a patient recording their visit? Would this change if the provider was asked ahead of time?
6) You are one of 10 participants who agreed to be interviewed from a total of 38 respondents who said they would not record their clinical encounter. What do you think kept those others from agreeing to be interviewed? What are potential differences among those who might record from those who wouldn't?

Appendix 2 **Details of interviewees included in this study, by category (n=17)**

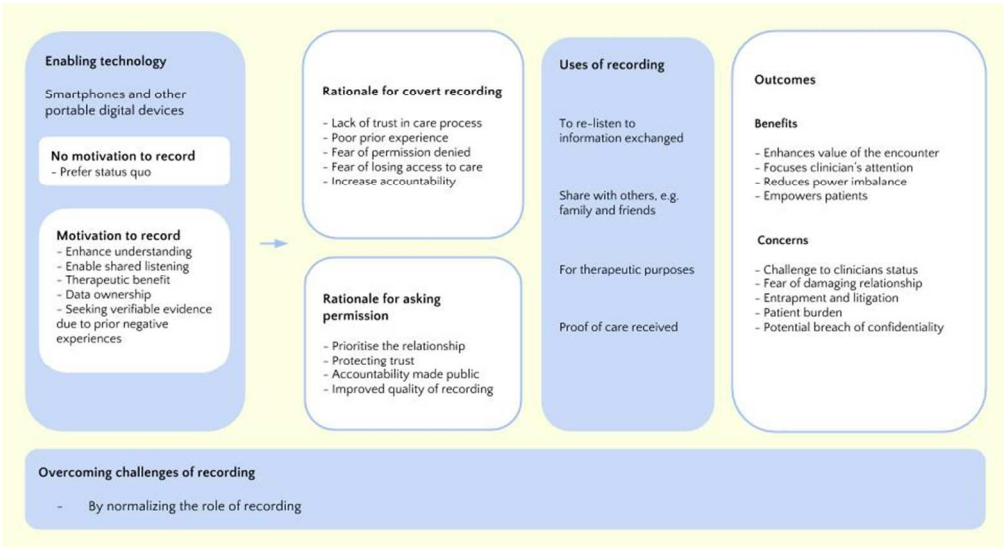
Demographics	Would ask permission (n=7)	Would secretly record (n=5)	Would not secretly record (n=2)	Have recorded secretly (n=3)
Gender				
Male	0	3	1	3
Female	7	2	1	0
Other	0	0	0	0
Age				
18-40	1	1	0	1
41-60	3	4	1	1
>60	1	0	1	1
Education				
Degree or higher professional qualification	7	5	2	3
Language other than English spoken at home				
Yes	1	0	0	0
No	6	5	2	3

A competing interest declaration.

This should be composed after each author has filled in the International Committee of Medical Journal Editors' Unified Competing Interest form and the corresponding author should keep the completed forms in case they are required later. Please then add to the manuscript a statement in the following format: All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare that (1) [initials of relevant authors] have support from [name of company] for the submitted work; (2) [initials of relevant authors] have [no or specified] relationships with [name of companies] that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have [specified] financial relationships that may be relevant to the submitted work; and (4) [initials of relevant authors] have no [or specified] non-financial interests that may be relevant to the submitted work."

License

"The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, a worldwide licence to the Publishers and its licensees in perpetuity, in all forms, formats and media (whether known now or created in the future), to i) publish, reproduce, distribute, display and store the Contribution, ii) translate the Contribution into other languages, create adaptations, reprints, include within collections and create summaries, extracts and/or, abstracts of the Contribution, iii) create any other derivative work(s) based on the Contribution, iv) to exploit all subsidiary rights in the Contribution, v) the inclusion of electronic links from the Contribution to third party material where-ever it may be located; and, vi) licence any third party to do any or all of the above."



338x183mm (72 x 72 DPI)