

Title: Evaluating nuanced practices for initiating decision making in neurology clinics

Summary

This proposed follow-up study aims to: a) further investigate the nuanced conversational practices involved in decision-making in patient-consultant interactions, b) directly compare three alternative practices for initiating decision-making (option-listing, patient view elicitors and recommendations), and in turn, c) develop a model of 'best practice' that can be easily communicated to consultants to further improve their patient-based interactions to achieve optimal outcomes.

This research follows on directly from our previous HS&DR-funded project (10/2000/61), which successfully met its objective to identify the key communication practices that neurologists are using to offer patients choice. In that previous research, we found that when doctors listed options from which patients could make a decision about which course of action to follow, both clinicians and patients perceived that offering a choice had been enacted. However, some complicating factors arose. For example, the practice of option-listing is also used by doctors to do actions other than offering choice. So, for example, we have cases where the machinery of option-listing is used to 'back the patient into a corner', amounting in practice to a form of recommendation. What this indicates is that it is not a straightforward matter to say: use practice X and patient choice will be achieved. Precisely how the practice is employed can have very significant consequences for patient responses and the type of 'slot' that the doctor creates for the patient. There was some evidence that patients struggled to make a choice and/or did not want to, including explicit attempts to get the neurologist to give a recommendation. Therefore, a more complex picture emerged from the data than anticipated, which raised the need to interrogate our data in more depth.

In order to further unpack what exactly is happening in patient-consultant interaction and how the different modes of decision-making impact on patient experience, we seek funding to further understand the complexity of this highly nuanced interactional work. In order to achieve this, we propose a mixed methods secondary analysis of our existing data.

- First, we will adapt Framework Analysis to map out: a) the three interactional practices we have previously identified for initiating decision-making in the neurology clinic (full-form option-listing, PVEs and recommendations), together with b) their interactional consequences (e.g. evidence from the recorded consultations of patient engagement or resistance, whether a choice was made and by whom). This will allow for qualitative comparison of the three practices.
- Second, drawing on the Framework Analysis, we will produce numerical coding of the qualitative data. This will allow for statistical exploration of the associations between the use of the three practices and a range of outcomes (both interactional and self-report).

This mixed method approach will enable us to compare doctors' recommendations with their efforts to hand the decision over to the patient. To our knowledge, this is the first time such a comparison has been made. In so doing, we aim to tease out the various interactional consequences, and consequences for patient satisfaction, of initiating decision-making in these contrasting ways. Our findings should give doctors nuanced guidance on how best to engage patients in the decision-making process, in ways that are acceptable to patients

themselves. Although our research will focus on neurology, we aim to produce clear guidelines of practical value to clinicians working in a range of settings.

Background and Rationale

Our previous research reflected the emphasis – within Department of Health and NHS policy documents – on patient choice¹, and the concomitant lack of evidence-based guidance for clinicians on how to enact this in practice. For example, laid out clearly in the *NHS 2013/14 Choice Framework*, there is a series of legal ‘rights to choose’, which all patients are accorded [2]. These include choosing one’s General Practitioner (GP) practice, having a right to ask to see a particular GP or nurse, choosing where to go for a first outpatient appointment if referred to secondary care, and which consultant will be in charge of one’s treatment. Moreover, a broader notion of patient choice is evident within NHS policy. Based on the Government’s vision for a NHS that puts patients first, and where ‘no decision about me without me’ [3] (p.3) is the guiding principle, the 2013 NHS Constitution [4] promises that, ‘patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment’ (p.3). This commitment to involving patients in shared decision-making was recently reinforced in comments made by the outgoing Chief Executive of the NHS, David Nicholson, who argued that changes in the NHS ought to be underpinned by a system that ensures, ‘citizens are fully empowered and included in all aspects of the NHS’ [5].

How to theorise and foster “shared decision-making” has thus been of great research interest. A major output has been a range of models, which identify key characteristics of a shared approach [6]. However, the research to date has two main limitations: First, most of it has been largely theoretical or based on retrospective data (e.g. interviews after the clinical encounter), rather than involving analysis of real consultations. Where observation has been used, interactional details have typically been lost through coding. This is a problem, since interview studies suggest that patients associate greater choice with a range of interactional practices that would not be coded as such (e.g. answering questions and indicating an interest in the patient’s perspective) [7]. To investigate the subtleties of clinician-patient interaction, a fine-grained analytic approach is needed. Second, as a consequence of this reliance on retrospective data and coding, only general recommendations for effective practice are usually offered. For example, Charles et al.’s widely cited model of shared decision-making does not explicate how to implement its components in interaction with patients [8]. General guidelines tend to be repeated in information given to doctors. For example, the General Medical Council’s guidelines for ‘Good Medical Practice’ [9] simply informs doctors to listen to patients and to take their views into account but gives no guidance on this might best be achieved. There exists, then, a gap between policy and practice [10] and it is to address this gap that both our original and current projects are aimed.

However, our previous study produced complex findings that caution against mechanistic guidelines and highlighted a pressing need for nuanced understanding of how interactional practices work flexibly to produce different outcomes. The data illustrate that the process of generating ‘choice’ through practice is more complex than simply ensuring doctors adhere to a protocol of, say, option-listing for the reasons listed below. This means that further research

¹ The concept of ‘patient choice’ is a contested one, used in diverse ways across different academic, political and policy literatures 1. Elwyn G, Miron-Shatz T. Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations* 2010;**13**(2):139-47 doi: 10.1111/j.1369-7625.2009.00572.x[published Online First: Epub Date]]. We acknowledge the complexities but for the sake of clarity we adopt a model of choice that places decision making at its heart.

is necessary in order to be able to make recommendations about how 'choice' might best be achieved in practice. Specifically, our data revealed the following complexities:

- 1) The practice of option-listing could also be shown to be used by doctors to do actions other than offering choice. So, for example, we have cases where the machinery of option-listing is used to 'back the patient into a corner', amounting in practice to a form of recommendation. What this indicates is that it is not a straightforward matter to say: use practice X and patient choice will be achieved. Precisely how the practice is employed can have very significant consequences for patient responses and the type of conversational 'slot' that the doctor creates for the patient.
- 2) There was some evidence that patients struggled to make a choice and/or did not want to, including explicit attempts to get the neurologist to give a recommendation.
- 3) There was some preliminary evidence to suggest that recommendations themselves can be designed so differently that they are probably best thought of as lying along a continuum from something akin to a directive to something that is potentially hearable as choice for the patient.
- 4) When doctors offered patients choice about a single option using a patient view elicitor (PVE)², the detailed qualitative analysis indicated that patients typically appeared to be declining these offers.

A more complex picture emerged from the data than anticipated, which raised the need to interrogate our data in more depth. It is to support this more nuanced work that we are seeking a follow-on bid to our previous research. We propose adapting the method of Framework Analysis (FA) [11 12] in order to map out our qualitative and quantitative data to support comprehensive explanatory analyses of the various interactional approaches we identified and the ways these might be linked to variables for which we have data: patient satisfaction, health status, and demographics. FA permits the systematic identification of complex patterns without losing the depth and richness of qualitative data; in essence it achieves, 'a holistic descriptive overview of the entire data set' [13] (p.118). The complexities of our original findings caution against the adoption of a single, definitive set of guidelines. The principal objective of FA is to provide a nuanced framework (or model) to inform policy and practice, and is consequently a good fit for our overall aims to produce flexible and detailed guidance for practitioners. Whereas FA normally reflects coded content (themes), we intend to adapt this method to illustrate sequences of interactional activities (identified by conversation analytic methods). In addition to using FA to produce a matrix of conversational activities involved in clinical decision making processes, we propose to use the adapted method of FA to develop numerical coding that will permit quantitative analyses to provide statistical support for what works 'best' for patients in terms of offering (and responding to) choice. In the next section, we unpack the complexities of our original findings in order to substantiate the need for further analysis.

Previous HS&DR Study: Findings and Complications

Based on the well-evidenced understanding that even small differences in doctors' communication practices can have a significant impact on the ensuing interaction and, in particular, on patients' involvement therein [14-16] we used an approach (known as

² A PVE is when a single option is offered to the patient but followed up with a specific attempt to seek the patient's view (e.g. 'is that something that would interest you?')

Conversation Analysis) that focuses on the detail of talk. This entails the fine-grained, qualitative analysis of doctor-patient interactions, recorded during real consultations. We collected video and/or audio-recordings (depending on patient preferences) of 223 neurology consultations, which took place in outpatient clinics in Sheffield and Glasgow. On this basis we were able to identify several ways in which neurologists were demonstrably seeking to offer patients choice about treatment or further investigations (discussed further below). Participating neurologists and patients were also given a post-consultation questionnaire, which included an item asking whether the patient had been offered a choice during the just-completed consultation. This gave an additional indication of the *perception* of choice for the recorded consultations. Table 1 summarises the extent to which neurologists and patients agreed on this (note that questionnaire data were missing for 27 cases).

Table 1: Agreement and disagreement about presence of choice

	Neu: Choice	Neu: No Choice
Pat: Choice	Subset 1. Agree (n=105)	Subset 2. Disagree (n=35)
Pat: No Choice	Subset 3. Disagree (n=28)	Subset 4. Agree (n=28)

By dividing our recorded consultations into the subsets shown in Table 1, we were able to interrogate the relationship between perceptions of choice and the range of practices (evident in the interactions) that neurologists were using to initiate decision-making. A striking finding emerged from our comparison of these four subsets. The practice of option-listing – which we first identified in our pilot dataset as a practice for giving patients choice [16 17] – was present in *only one* of those subsets in our full collection of recordings: the consultations for which neurologist and patient *agreed that a choice had been offered to the patient*. We described the full-form of option listing as containing the following three components: An announcement by the neurologist that there is a decision to be made; the formulation of a list of options; an invitation to the patient to announce their views with respect to the options or select an option from the list; the patient view elicitor (PVE). Taken together, our analysis of the self-report and the recorded data showed that option-listing was both perceived as offering choice (by neurologists and patients) and demonstrably treated as doing so in the consultation itself. These findings provide a strong warrant, then, for viewing option-listing as a canonical practice for offering choice.

On this basis, it would seem that our previous findings put us in a strong position for meeting a second main objective of the project: to provide effective practice guidelines to clinicians. In one sense this is the case. We are well-placed to provide guidance and training on *how to offer choice*; through the practice of option-listing. However, we are not, on the basis of this previous study, able to comment on how offering choice compares as an approach to initiating decision-making, with the alternative practice of recommending. Our previous analyses sensitized us to the ways in which being presented with a choice was sometimes resisted by patients, and in some instances led patients to actively seek a recommendation. We recognize a paradox here in that attempts by patients to abdicate choice involve their exercising the right not to align with the role of ‘choice-maker’ as set up (interactionally) by the

doctor. Hence, resisting choice is not necessarily evidence of patient passivity but can be interpreted as the patient deciding not to choose [18]. However, our main interest is that patient resistance to choice is evident at all, given both the strong directives for clinicians to offer choice, and the possible benefits that having choice may confer on patients.

There is in fact mounting evidence that patients react to choice in complex ways, and do not always welcome it [18-23]. Whilst some patients prefer to participate fully in treatment decisions, others prefer to leave the decisions to the clinicians. This variability leads some to argue against adopting a particular – one size fits all – approach, suggesting instead that a flexible and situated approach is more appropriate in order to respect individual preferences [18 24-26]. For example, Lee and Lin (2010) [18] found the relationship between what they call patient-centredness and levels of satisfaction held over time *only* for those patients who reported a high preference for autonomy. They conclude that, ‘patient-centered care must focus less intensely on normative thinking regarding participatory decision making as a means of respecting autonomy and pay greater attention to a broader set of ethical considerations relating to respect for patients as individuals’ (p. 1817). The acknowledgment of variability amongst patients complicates the argument that offering more choice is necessarily better for all; arguably, the rights of patients to opt out of greater involvement in decision-making ought to be treated with as much respect as those of patients whose desires and values are in line with current policies on patient choice.

Our previous project showed evidence for some of this patient ‘resistance’ to choice in practice. We noted that neurologists can treat a decision as lying in the patient’s domain by using option-listing to: construct a decision as yet to be made; suggest more than one option as a reasonable course of action; and, produce a slot for the patient to announce a view/select from the list at a point where the neurologist has not (yet) made a recommendation. In so doing, they can open up space for patients to *align* with the action projected by option-listing by selecting an option from the list. Certainly, in our data, there were cases where, having been invited to voice a view, patients did express a preference from the menu of options they had been offered. However, two other forms of response were also evident. Some patients *deferred* the relevant response by, for example, asking a question and thus managing to evade the constraint to produce a view. Once the patient’s question had been dealt with, however, that constraint became ‘live’ again. Hence, the patient would typically go on to produce another form of response. A third type of response was one that *countered* the action performed by the neurologist’s turn by placing responsibility for decision-making back in the neurologist’s domain (e.g. by responding with something like ‘it depends on what you think’). In effect, patients counter by seeking a recommendation, thereby resisting the neurologist’s attempt to hand the decision to them. The three forms of responses to option-listing are shown with illustrative examples in Table 2 below.

Table 2: Three forms of responses to option-listing

Align	Patient selects an option from list that’s been offered	<p>Neu: So it’s up to you</p> <p>Pat: .hh I’ll- I’ll:</p> <p>(0.2) I (will) go back to the GP and have me blood pressure taken and if it’s hi:gh then:</p>
Defer	<p>Patient holds off making a selection and instead asks a question.</p> <p>(In the example shown on</p>	<p>Neu: Either one of them, (0.3) grab you?(0.6)Any: particular preference, (0.5) one or other, (1.1)</p> <p>(Pat): hhh[hhhh.</p> <p>Neu: [It’s difficult</p>

	the right, the young patient responds with a form of laughter and it is his mother who asks a question, thereby deferring the selection of an option)	'cos they <u>both</u> work in relatively similar ways:. (0.1) Mum: I'm not [sure about the side effe:cts, but (.) has any of them got (0.3) no(se) weight lo:ss 'cos he's (0.1) (kinda) (a(h)wfully) thi(h)n (a(h)s it is
Counter	Patient places responsibility for making a decision back with the neurologist	Neu: .hhh How do you feel about being seeng another doctor, to have the (0.2) scans and the (0.2) CSF results: revie:wed. (0.4) Neu: D'you want to wa:it until you've (0.6) seen how you respond to the steroids or d'you want to (.) think about makin' an appointment with them. Pat: Whatever d'you think, as long as I don't have to go for that (.) spinal thing again 'cos I (cannae) do that again,

N.B. Transcripts simplified for clarity

In sum, our previous study met our primary objectives to identify key practices by which neurologists were offering choice (i.e. enacting NHS policy). However, like in previous self-report studies, we also found that patients sometimes have real difficulty responding to offers of choice. As a consequence, there is a pressing need for a follow-on study that compares those approaches to initiating decision making that index the neurologists' recommendation for what is best for the patient with those that place the decision in the patients' domain.

However, comparing two different interactional practices – option-listing and recommending - is a complex matter because the two practices set up different kinds of interactional responses from patients. Option-listing can be used to expressly invite patient views, and hearably places a constraint on patients to make a selection from the menu they've been offered. That is, option-listing (variably) places a decision in the patient's domain. In contrast, recommendations are better understood as proposals put forward by the neurologist to be accepted (or not) by the patient [27]. As Pilnick has argued, [28] there is a real difference between, 'a decision that simply requires assent to a recommended course of action, [and] the production of an independent choice' (p.519). Hence, a comparison between option-listing and recommending is not a comparison of like-for-like.

To complicate matters further, our previous analyses demonstrated that although option-listing readily generates a *perception* of choice it is not always clear from the interaction that an independent choice was actually achieved or wanted by the patient. Indeed, we showed a case where option-listing, instead of promoting choice, actually curtailed it. Here, the practice was evidently being used to try to direct the patient towards the neurologist's preferred course of action, while, nevertheless, implicating the patient in the decision-making process. Hence, although full form option-listing stands as the canonical practice for offering choice (at least in our dataset), it can, in fact, be used to do the opposite. This 'malleability' of interactional practices means that they cannot be taught, employed, or evaluated *mechanistically* (e.g. 'to offer a patient choice, use option-listing').

Moreover, the contrasting case of recommending cannot easily be described in terms of failing to offer patients choice. The ways in which recommendations are formulated construct

a continuum both with respect to the extent to which they incorporate the patient's perspective, and the extent to which they indicate that a response from the patient is relevant and expected. For example, in a series of influential studies of treatment decision-making between doctors and parents of children presenting with upper respiratory tract infections, Stivers [29-31] showed that when parents responded to treatment recommendations with a full acceptance (such as "Okay" or "let's do that"), doctors typically moved towards closure of the consultation. However, when parents responded with silence or minimal receipts (such as "mm"), doctors continued to talk about treatment, justifying their recommendation or revising it. On this basis, Stivers convincingly argued that the doctors were treating such responses as passive resistance and were hence working to secure a full acceptance before moving to close. Where this failed, patients were sometimes prescribed antibiotics even when these were medically unnecessary.

Comparable patterns are evident in other settings [27 32-35]. Moreover, Costello and Roberts [34] demonstrated that – whether or not patients display resistance – doctors in both oncology and internal medicine clinics routinely orient to the patient's right to accept or reject their recommendations through the interactional work they do to *justify* them. Medical recommendations may be understood, then, as a form of 'joint social practice' (p.241).

Taken together, once again these studies further sensitise us to the 'malleability' of interactional practices and demonstrate that clinicians cannot be taught mechanistically, say, to avoid making recommendations in order to ensure that patients are not excluded from the decision-making process. Nevertheless, as our previous study showed, recommendations do not *invite* patients to make a decision; and this contrasts with option-listing, which does.

Given the complexities of a simple comparison between option-listing and recommending, our aim with this bid is, in part, to see whether we can generate a methodological framework in which to explore them as contrasting practices. A good starting point is provided by another practice that we showed, in our previous study, to be frequently perceived as offering choice: the patient view elicitor (PVE).

The PVE appears in full-form option-listing as its final component. However, as we showed in our previous study, they also may be used independently of option-listing – as an alternative approach to initiating decision-making. Crucially, the decisions initiated with patient view elicitors are not constructed as a matter of selecting from a 'menu' of alternatives. Rather, they involve making a decision for or against *one possible course of action*. In this sense, they are closer to recommendations and represent a good option for initial comparisons. This said, PVEs have their own complexities. In our previous study, the collection of these 'single option' PVEs divided into two distinct groups: those where the possible course of action was introduced *prior* to the use of the PVE, and those where it was introduced *through* its use (see Table 3 for illustrative examples).

Table 3: Two forms of 'single option' Patient View Elicitors

Neurologist provides relevant information <i>prior</i> to PVE (shaded)	<p>Neu: And sometimes just by <u>t</u>reating the fatigue can impro:ve these symptoms. Quite significantly. And there are a few medications that we can try (0.2) to try and achieve that=s that something that would interest you.</p> <p>Pat: Ye↑::s uhuh,</p>
Neurologist introduces treatment option through the use of a PVE (shaded)	<p>Neu: but certainly that sounds very typical for a migraine aura, .hhhh A:re these >kind of< often enough that you would be wanting to try:: (0.6) a drug to try and redu:ce how (.) often it's happening.</p> <p>(0.3)</p> <p>Pat: .thhh U:m:: (1.1) .t (0.4) <u>yes</u>: I (sp-) <ye<u>eah</u>.</p>

We argued that both forms of PVE serve to place the decision in the patient's domain. However, we also suggested that each raises a potential difficulty for patient choice: PVEs produced after the neurologist has informed the patient about a possible course of action run the risk of being treated by patients as *recommendations* (and not a matter of choice) because the information may be heard as an indication of what the neurologist thinks ought to happen next (rather than as a neutral informing). By leaving out the prior information, neurologists may avoid this risk. However, they may, instead, leave the patient ill-equipped to respond to the PVE. Ironically, the patient may, on hearing a stand-alone PVE, recognise that s/he has a choice, but be unable to exercise it. Further, our impression from the detailed qualitative analyses was that when patients were being offered a choice about a single option, they appeared to be typically declining that option. Further qualitative and quantitative analysis is required to explore this and to test whether this impression is statistically significant.

In sum, our previous study showed that if doctors want to ensure a patient knows s/he has a choice, our detailed analyses show how option-listing can provide an effective strategy. Crucially, however, our findings also illustrate that simply asking doctors to adopt a practice (like option-listing) will not automatically lead to a patient-centred approach. We also found evidence that some patients struggle when invited to make a choice, and that they may actively seek a recommendation. Recommendations themselves ought not to be treated as automatically denying patients a voice. Nevertheless, they do not actively invite patient views. We also explored a third practice, the PVE, which invites patients' views on a single option. We noted these can raise difficulties for patient choice, and in fact appeared to lead (most commonly) to a rejection of the proposed course of action. Thus, although we achieved our primary objective in that study (to identify key practices being used by neurologists to offer patients choice), our study raised a vital question which it was not designed to answer in itself: how do the practices through which clinicians may offer choice compare with those practices through which clinicians may deliver a recommendation? i.e. a comparison of practices that broadly enact the same general activity (initiating decision-making about treatment/further investigations) but in very different ways (those that place the matter of what is best for the patient in the doctor's domain versus those that place the matter of what is best for the patient in the patient's domain). In the next section, we outline our plans for how we will conduct the new research.

Proposed Follow-On Project: Comparing and Evaluating Practices

We are making this bid in order to fund further research on our rich data set so that we will be in a better position to disseminate clear, systematic but flexible guidance on what 'works' best for patients and clinicians. To do this, we propose using an adaptation of Framework Analysis in order to generate a holistic and flexible mapping of the entire data set and then to use this in order to generate quantitative coding to allow for statistical analyses.

Framework Analysis (henceforth, FA) was developed by Ritchie and Spencer in the 1980s [11 12] as a way of managing qualitative data in large-scale social policy research and has become increasingly popular in medical and health research (e.g. [13 36-40]) that is policy oriented [36]. FA allows for systematic, rigorous and transparent management of qualitative data without losing the richness and flexibility of those data [39 41]. These are qualities that are valued in the conversation analytic method we have used previously [42]. However, insofar as FA is a formal system for *thematic* analysis, we will be using an adapted version that takes into account interactional practices rather than themes. As far as we know, there has been no attempt to map out specific practices across an entire data set of interactional

STH19071 Version 1.0 13/07/2015

data and to identify patterns and associations with a range of quantitative data. In this sense, our proposed research is both original and ambitious.

Following the mapping of the data, where possible and appropriate we would like to conduct statistical analyses to underpin the explanatory nature of the model we produce. Indeed, this is something we had proposed doing for our original project but in the feedback from the HS&DR Board's responses we were persuaded to leave this for a follow-on study. We were very appreciative of the Board's recognition of the value of conducting the foundational, fine-grained, qualitative analysis before proceeding to statistical study. We remain sensitive to the complexity of reducing nuanced interactional practices to homogeneous categories but can see the possibility for statistical analysis following a detailed adapted form of framework analysis that can be used to generate testable hypotheses.

This study will be the first to directly compare doctors' recommendations with their efforts to hand the decision over to the patient. In so doing, we aim to tease out the various interactional consequences, and consequences for patient satisfaction, of initiating decision-making in these contrasting ways. Our findings should give doctors nuanced guidance on how best to engage patients in the decision-making process, in ways that are acceptable to patients themselves. Although our research will focus on neurology, we aim to produce clear guidelines of practical value to clinicians working in a range of settings.

Why this research is needed now

The DH has been clear that a shift towards a shared decision-making model (especially for patients with long-term conditions) is needed. This study aims to contribute evidence-based recommendations to help clinicians enact this shift in practice in the most effective and acceptable ways. Building on our prior HS&DR-funded study, our key research questions have arisen out of our fine-grained analysis of what actually happens in neurology consultations. As we have outlined above, these have shown the complexities of the decision-making process. The need for this research, then, comes both from the top-down (policy) and the bottom-up (evidence from practice). Patient involvement in decision-making has been associated with improved physical and mental health outcomes but there is also evidence that patients may want differing levels of involvement and that some may even prefer to receive a recommendation from the doctor [18 19]. This study will be the first directly to compare doctors' recommendations with their efforts to hand the decision over to the patient. In so doing, we aim to tease out the various interactional consequences, and consequences for patient satisfaction, of initiating decision-making in these contrasting ways. Our findings should give doctors nuanced guidance on how best to engage patients in the decision-making process, in ways that are acceptable to patients themselves. Although our research will focus on neurology, we aim to produce clear guidelines of practical value to clinicians working in a range of settings.

Aims and objectives

Our previous research successfully met its objective to identify the key communication practices that neurologists are using to offer patients choice. In line with other conversation analytic studies, this research was intended to provide detailed foundational evidence about what clinicians actually do in interaction with patients, and was not designed to compare the effectiveness of those practices identified as methods for offering choice with the alternative practice of recommending. The primary purpose of this follow-on research is to do just that; we aim to document and evaluate any differences between three practices used by the clinicians in our dataset to initiate decision-making in interaction with patients: option-listing, patient view elicitors (PVEs), and recommending. Specifically, our objectives are to:

1. Map out: a) the three interactional practices we have previously identified for initiating decision-making in the neurology clinic, together with b) their interactional consequences (e.g. patient engagement or resistance, whether a choice was made and by whom);
2. Identify, both qualitatively and quantitatively, any evident *interactional patterns* across our dataset (e.g. whether one practice more commonly leads to greater patient engagement or resistance, and whether one leads more commonly to the patient making a choice);
3. Examine, statistically, the relationship between the interactional practices identified and the self-report data we have already collected (i.e. patient satisfaction data from the MISS-21 questionnaire and other variables, such as how certain the neurologist was of the diagnosis and whether or not the neurologist and patient thought a choice had been offered);
4. Use the findings from the above analyses to address our overarching aim of comparatively evaluating the three practices as methods for initiating decision-making with patients in the clinical encounter.

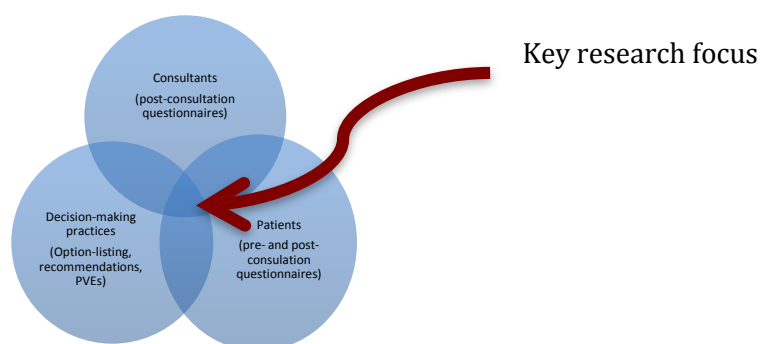
Taken together, these analyses will allow us to develop systematic but nuanced answers to the question of whether giving patients choice is better or worse than making a recommendation where these are assessed on a range of detailed qualitative and statistical measures.

The practical goal motivating this work is to provide evidence-based and contextualised (as opposed to abstract) guidance regarding how these practices actually work in order to enable clinicians to use them sensitively and holistically.

Research Plan

Design and theoretical/conceptual framework

We have a large and complex data set that comprises 223 consultations between doctors and patients in neurology clinics and a range of self-report (questionnaire) data associated with each consultation. Within the data set, we have already identified instances of and practices for initiating decision-making. Our data can be conceptualised in the following Venn diagram.



Our main research focus is on the intersection between these three broad categories of data: characteristics and self-reports of the patients and neurologists and the set of interactional practices they jointly produce. Please also see the additional uploaded document – ‘Diagram, data for use in follow-on study’ – for further clarity regarding our dataset and the relationship between the proposed follow-on study and the original work already conducted.

We propose, as a first step, to produce a ‘map’ of our data set using an adapted version of FA. As noted above, FA was developed with applied policy research in mind [11]. It is

suitable for managing and visualising large sets of qualitative data, with the aim of producing 'actionable outcomes' ([12], p. 173). It involves the development of a matrix that comprehensively maps out the data in a systematic and transparent way. It encourages deep contact with the qualitative data and incorporates multiplicity and display of diversity. So although in some senses it reduces the data to an organised and manageable form, it also maintains its richness and complexity. The aim is to facilitate interpretation of the data by reducing and visualising it as a holistic map of categories and the connections between them. The features of FA resonate in interesting ways with the conversation analytic approach we used previously. Both approaches are systematic, transparent, richly descriptive and contextual, and allow for complexity. For this reason we would like to find ways of combining the two. However, we will be adapting FA so that we can categorise interactional practices rather than themes.

We believe that the resulting matrix will be valuable in its own right as a way of highlighting important qualitative relationships between the categories. However, as a further step, we propose to use this inductively produced map to generate numerical coding of the qualitative categories. This will involve meticulously producing definitions of each practice (and their nuances) and categories of interactional responses. Having agreed definitions, we will produce a codebook to inform our selection of data. With this in place, the two conversation analysts on the team would work independently through the entire data set, coding data according to our agreed definitions.³ This will allow for a test of inter-rater reliability. The coded data will be converted to numerical values to permit appropriate statistical analyses. The exact analyses will emerge from the data but we are particularly interested in directly comparing the three major interactional practices we have already identified so that we can address the question of which approach is the most effective on a range of measures including but not limited to patient satisfaction.

Sampling

Our corpus of data derives from two research sites (in Sheffield and Glasgow). The study was conducted in the outpatient departments of two major clinical neuroscience centres (the Southern General Hospital in Glasgow and the Royal Hallamshire Hospital in Sheffield). The recordings were made between February and June 2012 in Glasgow, and between April and September 2012 in Sheffield. Fourteen clinicians (7 in Glasgow, 7 in Sheffield) agreed for recordings to be made in their clinics subject to patient consent. In total, 223 patients agreed to take part (114 in Glasgow, 109 in Sheffield). One appointment per patient was captured. In addition to patients and clinicians, 120 'accompanying others' (including spouse, parent, carer, and friend) consented to contribute to the study (63 in Glasgow, 51 in Sheffield). All participants consented for our recordings and transcripts to be used in future studies using different analytic methods.

Although substantially larger than the sample sizes attained for much qualitative research, similar samples are now commonplace in CA studies of medical interaction [14 43 44]. Working with 200 plus recordings is both feasible and desirable for the present study. We have previously employed this approach successfully with a similar sample size [45]. Larger datasets are desirable for CA research because, they provide more instances of the same action (offering choice), making it easier to identify patterns and deviations from these [46].

Setting/context

³ MT has direct experience of coding a data set in this way, as part of an international team of conversation analytic researchers working under the direction of Professors John Heritage and Tanya Stivers, UCLA.

Our data comprises consultations conducted in the outpatient departments of two major clinical neuroscience centres (the Southern General Hospital in Glasgow and the Royal Hallamshire Hospital in Sheffield).

Data collection

We are not intending to collect new data for this project. We are proposing a secondary analysis of data that we have already collected. The qualitative data consists of the 223 recordings of medical consultations in the neurology clinic. The quantitative data comes from sets of self-report data collected at two points:

The pre-appointment questionnaires (for patients) captured:

- Demographic details (including age, gender, ethnicity, and socioeconomic status);
- Self-reported patients' health-related quality of life (using the 12-item Short-Form Health Survey (SF-12));
- The patient's agenda ("Please list your reasons for seeing the doctor today, including the problems you want to talk about and any tests or treatments you hope to receive");

The post-appointment questionnaires captured patients' impression about whether they were given a choice using a short series of questions, devised for that study (e.g. were they given a choice; if they had a preference; was this reflected in any decisions reached; do they think the clinician had a preference).

In addition, the post-appointment questionnaires contained:

- The Medical Interaction Satisfaction Scale 21 (MISS-21), which has been validated in UK patient populations, and used in previous CA research to measure patient satisfaction with consultations in primary care

Similarly, clinicians completed a short post-appointment questionnaire, devised for the study, about the diagnosis (how certain it is) and any decisions reached (e.g. did the clinician have a preference; did they think the patient had one; did they offer a choice and how satisfied did they feel the patient was).

These self-report data will allow us to produce a quantitative evaluation of the interactional strategies identified in the previous study. This is an increasingly common approach when applying CA to medical interactions: the foundational, fine-grained, qualitative analysis is done first, followed by various statistical measures of evaluation [22]. In particular, the follow-on research would draw on the design of a previous study, which showed a statistically significant relationship between clinicians' opening questions and patients' satisfaction with the consultation [43].

Qualitative data analysis

All recordings were transcribed verbatim, anonymised, and analysed using conversation analysis (CA). CA is a qualitative, micro-analytic, systematic method for studying real-life interaction. It is widely recognised as the leading methodology for investigating how doctor-

patient communication operates in practice [21, 22]. It uses audio- and video-recordings of authentic interactions to enable direct observation and fine-grained analysis, focusing not only on what is said but *how* it is said (e.g. the exact words used, and evidence of hesitation, emphasis, interruptions, laughter or misunderstanding). Its key advantages are that it does not rely on recall – which can often be incomplete or inaccurate [24] – and it investigates how people behave at a level of detail that they could not be expected to articulate (e.g. in a research interview).

The conversation analytic work carried out on this dataset in our original study has already identified the three key decision-making processes in the dataset that will form the focus for the proposed follow-on work. These processes would be the particular focus of this new project.

With the conversation analytic work in place, we will proceed to the adapted Framework analysis, which involves five interconnected and dynamic stages.

1. **Familiarisation:** This is essentially immersion in the data, familiarising ourselves with their interactional shape and content.
2. **Identifying a framework of practices:** Drawing on the interactional practices we have already identified as the major analytic impetus and paying greater attention to the complexities of relationships between these and a range of patient responses including interactional responses and data from self-report questionnaires. In essence this stage involves categorising all interactional activities in the decision-making processes previously identified in our entire data set.
3. **Indexing:** Produce a qualitative coding system that covers the analytic practices identified above. This involves identifying portions of the data that correspond to categories agreed for stage 2.
4. **Charting:** Lifting data (coded interactional practices) from its original context and placing them on a chart of categories already identified.
5. **Mapping and interpretation:** Analysis of key characteristics as laid out on the chart leading to explanatory accounts of the data. It is at this stage that recommendations for practice will emerge.

As noted above, we believe that the analytic processes and outcomes of this qualitative coding and mapping of the interactional activities involved in different decision-making processes will be useful in its own right. However, as leading conversation analysts (especially those working in the field of doctor-patient interaction) have been arguing for over a decade now, it is necessary to combine qualitative, CA-based findings with further statistical analysis if we are to answer an important type of research question – that which Heritage refers to as ‘distributional’ in nature [47]. In this category he includes questions about the possible relationship between interactional practices (understood as independent variables) and *outcomes* of various kinds. One prominent example – on which our proposed approach is modelled – involved statistical comparison of the effect of GPs’ use of open-ended vs. closed questions for eliciting patients’ presenting concerns on patients’ subsequent report of satisfaction with the visit [48]. This study showed that the open-ended format was associated with significantly higher scores on key items of the Socioemotional Behavior subscale of the Medical Interview Satisfaction Scale (the MISS-21, which we have also used in our study). In such studies the outcomes of interest are *external* to the clinical consultation (e.g.

questionnaire scores). Other studies have investigated the relationship between interactional practices and outcomes that are *internal* to the consultation. For example, Heritage showed that patients were significantly more likely to reveal, *during* the consultation, additional medical concerns they had (other than their main reason for attending) if the GP asked if there was “*something else*” rather than “*anything else*” that he/she could do for the patient [14]. Whether focusing on internal (i.e. interactional) or external outcomes (i.e. some kind of additional measure, such as questionnaire), however, such distributional questions cannot be addressed adequately through qualitative methods alone. As Robinson puts it: “*comparisons of the operation of different CA practices do require statistical evidence*” [49] (p. 74, italics in the original).

Findings like those summarised above depend crucially on the quality of the foundational conversation analytic research [47–49]. This is because any attempt to ‘code and count’ is meaningless if the practices for which one is coding are not clearly described and thoroughly understood. In the examples outlined above, the statistical analysis was – as in our proposal – based on solid findings from extensive prior conversation analytic work. We strongly agree with Robinson’s (2007) argument that:

Prior to statistical testing, analysts need to be able to answer at least the following questions *in specific terms*: What is the claimed practice (i.e. what are its constitutive features as an orchestration of conduct-in-interaction), the action(s) it accomplishes, the norms/rules it instantiates, and its range of interactional consequences? (p. 74).

This is why our previous study focused exclusively on describing and explicating, in fine-grained qualitative detail, the practices neurologists were using to offer patients choice. It is also the reason for devoting a significant proportion of this follow-on study to further qualitative work to ensure that our coding is robust and thoroughly rooted in the nuanced interactional realities at play in each consultation. However, we also have a range of research questions that cannot be answered by qualitative means alone. Crucially, we want to be able to conduct meaningful *comparative* analysis regarding the possible effects of our three core interactional practices (option-listing, PVEs and recommending) on outcomes that are both interactional (e.g. who, within the consultation, makes the decision, is there evidence of patient resistance of some kind, is there evidence that one or other party gets ‘what they want’ etc.) and self-report-based (e.g. patient satisfaction scores, whether participants thought the patient had been offered choice, a measure of the patient’s physical and mental well-being). In the next section, we describe the methods we intend to use to allow us to do this.

Quantitative data analysis

The formulation of testable hypotheses will come late in the exploratory research process that will be used in this study. The statistical methods employed will be contingent on the results of the Framework Analysis. Additionally, due to the relatively small sample size (N=223), the extent to which complex multivariate techniques can be employed is limited. Despite these caveats restricting the certainty with which we can outline what the exact research process will be, it is clear that the main crux of the analysis will be a focus on the associations between the communication strategies used by doctors and a variety of different variables that may come from one of three sources:

1. Categorizations resulting from the coding process conducted in the Framework Analysis.

2. The pre-appointment questionnaires (e.g. demographics and physical and mental health measures in the form of the SF-12 questionnaire)
3. The post-appointment questionnaires (comprised of the MISS-21 scale, which provides indicators of patient satisfaction, a separate questionnaire focusing on choice and shared decision making, and a questionnaire completed by the neurologist on the same topic)

Initial analyses conducted will consist of bivariate analyses in the form of tabular and graphical representations of the relationships between different variables from the sources listed above. This stage of the analysis will serve two purposes. First, it will provide an initial opportunity to explore whether qualitative relationships between different interactional practices identified in the Framework Analysis (that will have been operationalized as quantitative measures through processes of categorization described above) can be replicated quantitatively. Second, output based upon graphical and descriptive analyses is easily understandable by stakeholders without statistical expertise, and thus provides an appropriate way to disseminate findings to such groups.

With respect to the interactional outcomes of this research (i.e. those that are *internal* to the consultations we recorded), we will examine the extent to which each of the core interactional practices used by neurologists in our dataset (i.e. recommending, option-listing, and using patient view elicitors) show bivariate association with subsequent interactional practices used by patients (such as patient resistance or willingness to make a choice and resistance or willingness to accept a recommendation). A sense of how different forms of interactional practice may be associated with each other will have emerged qualitatively through the Framework Analysis process but this subsequent statistical work will allow for a quantitative investigation of these issues. For example, we will use cross-tabulations to investigate whether there is any relationship between communication strategies and, alignment / misalignment between the patient and the doctor.

We will also investigate the bivariate relationships between communication strategies and factors *external* to the consultations. Here, variables from patient and doctor questionnaires will be introduced into the analysis. One relevant variable here will be the MISS-21 scale, which is a widely used and validated [50] measure of patient satisfaction. As well as employing this scale as an overall measure of patient satisfaction, we will also employ separate components of the scale within the study. Preliminary exploratory factor analysis conducted on our MISS-21 data has revealed four different components that we have labelled 'Rapport', 'Distress-Relief', 'Doctor's Understanding', and 'Communication Difficulties'. Of particular interest may be the 'Rapport' dimension, which is made up of six items including 'The doctor seemed interested in me as a person' and 'The doctor seemed warm and friendly to me'. As such, this factor could be seen as an affective-relational subscale. Variables derived from answers to the post-questionnaire about patient choice will also provide potentially

fruitful avenues for empirical investigation. On this instrument, the key question is “Did the doctor give you a choice about any tests or treatment you might have or the next step in the management of your condition?” There may also be interesting relationships between interactional patterns evident in the consultations and self-report data from the doctors’ post-appointment questionnaires (e.g. certainty of diagnosis, degree to which the problem was medically explained, how well the consultation seemed to go).

It may be illuminating to see which, if any, of these *external* (self-report) variables are associated with particular communication strategies or interactional patterns. A similar strategy (of looking at the associations between self-report measures of patient satisfaction and categories derived from conversation analytic studies) has been employed successfully by other researchers working in the same field. For example, as noted above, Robinson and Heritage [51] have shown that an affective-relational subscale of the MISS questionnaire is associated with different formats of opening questions in primary care interactions.

The associations between these indicators of patient satisfaction and choice, and the categorisations derived in the Framework Analysis will therefore be investigated in the initial exploratory stage of the quantitative analysis. To give specific examples, we will use descriptive bivariate measures such as cross-tabulations and comparisons of means to explore whether there are associations between measures of patient satisfaction and choice, and interactional practices such as option-listing or recommending. It will also be possible to investigate the associations the measure of patient choice and the more established and validated MISS-21 scale, where the question of patient choice is not explicitly addressed.

Heritage [47] suggests that conversational practices could also be employed as dependent variables in quantitative research. In this case, exploratory data analysis could also be used to investigate whether certain categories of patient (whether these be demographic categorizations of people, or categorizations that arise from the Framework Analysis process) are associated with different interactional practices.

After these initial exploratory analyses have been conducted, a multivariate modelling process will be conducted, so as to explore these, and similar questions, while controlling for confounding variables. To give one example of the sorts of analyses that will be conducted in this stage, multiple regression models will be estimated with the MISS-21 scale, and different components of the MISS-21 scale, acting as dependent variables. Communication strategies, as well as control variables (such as demographics, measures of patients’ physical and mental health, whether or not patients attended clinics on their own or were accompanied by others, and whether or

not patients were meeting the doctor for the first time) will act as independent variables. This modelling process will facilitate an investigation of the extent to which different communication strategies may be linked to participants' evaluations of doctors' communication. Logistic regression will also be employed to explore the extent to which different communication strategies, and other interactional practices, are associated with perceived patient choice (as measured through the relevant variable described above), after controlling for other relevant independent variables.

A further analytic strategy we will follow is the identification of different categories of participant in terms of patient satisfaction. So, for example, we will identify patients who were relatively satisfied with their consultation and patients who were not satisfied (for example, through a median split of the MISS-21 scores, or a median split of scores on different components of the MISS-21 scale) and investigate the associations between such a binary variable of patient satisfaction, and independent variables such as demographics and interactional patterns.

It is important to note that the extent to which large numbers of independent variables will be able to be included in these models will be restricted because of the relatively small sample size available. Having said this, the application of quantitative methods to interactional data is a small and growing sub-field within the larger discipline, and this research represents an opportunity to expand upon work in this area. Small sample sizes are necessarily going to be an issue due to the logistics of data collection and existing applications of quantitative methods using interactional data have used comparably small sample sizes with some success (see [31 51 52]). We would suggest that, at this early stage in the application of such methods in CA-based studies, it is necessary to work with the data that are available, in part so as to show the potential efficacy of such studies, so that larger N studies can be conducted in future.

Dissemination and projected outcomes

Results of this study will inform development of detailed guidelines for clinicians about: how to best facilitate patient choice; the likely outcomes of particular practices both interactionally and in terms of statistical measures of effectiveness, and to develop a nuanced understanding of different practices (e.g. *not* treating recommendations as effectively eliminating choice nor seeing PVEs as a simple way of ensuring that patients do have choice). The overall dissemination strategy will be facilitated by the team's close links with professional organisations such as the British Medical Association, Royal College of Physicians, Association of British Neurologists and the International League Against Epilepsy. Results will also be disseminated to health care professional, policy makers and academic researchers, patients and their carers. Specifically, findings will be disseminated in the following ways:

Dissemination to healthcare professionals and policy makers: the main output of the study will be detailed guidelines for clinicians about (i) how best to facilitate shared decision making and (ii) what pitfalls to avoid. The guidelines will form the basis of two national level workshops hosted by the Universities of Sheffield and York each lasting half a day. In order to ensure the most appropriate audience, the workshops will be organised in collaboration with the Neurological Alliance. The workshops will provide an interactive forum in which to engage

with clinicians and policy-makers, review the study results and present the implications and guidelines. Service Users will be involved in preparing and delivering these workshops.

The team has also consulted with a number of clinicians and medical educators from a range of specialties in order to ensure that we have a strategy in place for dissemination beyond neurology. We have secured commitments to assist with dissemination from the following:

- Dr Anna Hammond, a GP who is also the Director of Communication skills teaching at the Hull York Medical School (HYMS);
- Dr Jean McKendree, Senior Lecturer in Medical Education at HYMS, who is also a General Medical Council Education Associate and is on the visiting accreditation teams for Plymouth and Exeter Medical Schools;
- Dr Rizwan Malik, who has just completed an Academic Clinical Lectureship in Ophthalmology at the NIHR Biomedical Research Centre at Moorfields Eye Hospital & UCL Institute of Ophthalmology. He has done some preliminary work with the applicants on using CA in Ophthalmology and, in the longer term, aims to apply the findings of the current study to Ophthalmology practice;
- Dr Danielle Jones, Lecturer in Dementia Studies at the University of Bradford, who contributes to specialist training for GPs and researches ways in which communication with people living with dementia might be improved.

Dissemination to academic researchers: the study results will be submitted for publication within peer reviewed journals, with a methodological paper submitted for publication to a health communication journal and at least one within an international, peer-reviewed healthcare journal. The results will be presented at appropriate international healthcare and communication conferences. In addition, the study and results will be presented to academic researchers and healthcare professionals through relevant seminars, including the Department of Sociology's departmental seminar series at the University of York, and at the Grand Round for medical members of staff at Sheffield Teaching Hospitals NHS Foundation trust.

Dissemination to patients and their carers: in addition to the provision of a full report, technical appendices and executive summary, a lay summary of the study's findings will be prepared with input from the proposed Service Users' Groups and made available in written and, where appropriate, podcast format to key patient websites and newsletters. Members of the Service Users' Groups will be actively involved in the two workshops and in the dissemination of research findings to other service users (e.g. through patient networks such as the Neurological Alliance).

Plan of investigation and timetable

This project will start 1 August 2015 and end 30 April 2017. The following table shows the scheduling of all major stages of the project, including the timing of key milestones and production of outputs.

Minus Month	<i>Secure ethical clearance to secure access to data for named changes in research team</i>
-------------	---

1-3 months	<i>Meetings:</i> Full team meeting to consider statistical coding of qualitative data. Service Users' Group to inform understanding of patient engagement with and resistance to shared-decision making. Set up a Steering group. Working with MT, CJ to familiarize herself with conversation analytic data set.
End month 3	Milestone: Complete 'familiarisation' stage and begin to develop qualitative framework.
Month 3-6	<i>Meeting:</i> Full-team and steering group meetings to assess progress. MT and CJ to have completed development of framework categories
End month 6	Milestone: Completion of coding of qualitative data in preparation for indexing and charting of data
Month 6-12	Full team to examine mapping and interpret data. Agree numerical coding where relevant. Two full team meetings and one steering group meeting to assess progress. Meeting with service users to discuss preliminary findings. Full team to write first journal article based on qualitative analyses (others to follow post-funding).
End month 12	Milestone: First output based on adapted FA
Month 12-15	PC and MR to conduct statistical analyses. PC, CJ and MT to organize dissemination workshops, write information for relevant websites and organisations. Full team meetings to discuss progress and findings from statistical analyses. Write second journal article.
End month 15	Milestone: Second output based on statistical analyses
Month 15-18	Full team and steering group meetings to discuss progress <i>and</i> plan final report. PC, CJ and MT to begin final report.
End month 18	Milestone: Draft final report submitted.
Month 18-21	Plan dissemination strategy. Run two dissemination workshops. Work with clinical members of Steering Group and other members of our networks to ensure dissemination beyond neurology. Work with service users group to ensure appropriate dissemination to patients and carers.
Post-project	Further publications

Project Management

MR will have overall responsibility for the project, including managing the budget, setting up Service Users' Group and Steering Groups, and overseeing the final report and dissemination of findings. He will also co-supervise the Research Associate. MT will be responsible for day-to-day project management, liaising closely with MR. The team has established successful patterns of collaboration (using email, telephone, conference calls and face-to-face meetings) during the previous study. They will build on this to facilitate liaison across the team in three main ways: i) Four SG meetings, which will include all co-applicants, plus two service users and two experts (one clinical, one in communication); ii) Six full team meetings to discuss progress and plan subsequent phases of the research; iii) Regular email/telephone/conference calls, as appropriate.

Approval by ethics committee

The original study was awarded ethical approval by the NRES Yorkshire & The Humber, South Yorkshire. MR is registered as the custodian of the data which we will use in the proposed follow-on study for the purposes of secondary analysis. We will seek additional approval in order to manage changes in the research team.

Patient and public involvement

During our original HS&DR study, we formed a Service Users' group, which met regularly across the life of the project to help inform every stage of the research process, including informing our study aims, designing our questionnaires and information leaflets, commenting

STH19071 Version 1.0 13/07/2015

on our findings in progress and working with us directly on some of our data analysis, and giving us access to patient groups for dissemination purposes. These discussions have significantly contributed to our understanding of service user perspectives on decision-making in neurology. Crucially, lively debates about what constitutes 'choice', reminders that patients do not always want choice, and challenging questions about whether choice should always be conceptualised as a 'good' thing have been significant 'push' factors in encouraging us to develop the present follow-on proposal.

Two service users from our original Service Users' Group (Rob Wilks & Andrew Myers, with experience of epilepsy and Parkinson's Disease, respectively) are keen to continue their involvement. At least one additional member will be recruited. Given the success of our original group, we will take the same approach, holding regular informal meetings, which aim to: i) present work-in-progress and data extracts for discussion; ii) seek reflections derived from service users' experiences of relevance to the research questions; iii) seek help with ensuring lay summaries are suitable for their intended audiences; iv) draw on service users' networks to facilitate dissemination; v) include service users as co-facilitators at dissemination workshops. This group will thus support the project in a range of practical ways and by keeping our analyses grounded in the perspective of those with experience of the services we are examining. Support will be provided by MT, MR and CJ at each meeting. We will also seek to provide formal training if desired (e.g. the DPH course, "Understanding the Research Process – A Guide for PPI Panel Members")

Expertise and justification of support required

The staffing and non-staff resources requested have been limited to essential resources necessary to carry out and disseminate the project effectively, ensuring sufficient resource and value for money.

1. Staff costs

The core research team consists of: i) a research active neurologist (Markus Reuber, MR), ii) an experienced researcher in medical interaction (Merran Toerien, MT), and iii) an early career researcher with expertise in conversation analysis (Clare Jackson, CJ). In addition, an early career researcher with quantitative expertise (Paul Chappell, PC) will be employed as a full-time Research Associate for nine months. An experienced quantitative methodologist (Emma Uprichard, EU) will act as a consultant on the quantitative component of the project for nine months. Here we outline each member's contribution in justification of the support required.

MR (Professor of Clinical Neurology and Honorary Consultant) will have overall responsibility for the project (see Project Management, above), and will work with PC on the quantitative element of the study and with MT and CJ on the qualitative analysis and the dissemination of the findings. He will spend 0.05 fte (1 hr/week) on this study for 21 months.

MT (Lecturer) will be responsible for day-to-day project management and will lead on the qualitative analysis and dissemination. She will spend 0.2 fte (1 day/week) on this study for 21 months.

CJ (Lecturer) will be responsible for qualitative analysis and dissemination. She will spend 0.2 fte (1 day/week) on this study for 21 months.

All co-applicants will attend SG and team meetings and contribute to the final report and dissemination of findings. The time allocations reflect the different responsibilities of team members. Since the qualitative work is time-intensive, MT and CJ have been costed for more time.

PC (Research Associate) will work alongside MT and CJ at the University of York, but under the co-supervision of MR. PC will work full time on the project for nine months and will be responsible for conducting the quantitative analyses. His research uses innovative quantitative methods and methodologies.

EU (Consultant) will provide additional statistical support and expertise for the nine months during which PC and MR are conducting the quantitative component of the study.

2. Non-staff costs

Travel and subsistence

Support has been requested to allow for the following essential meetings, workshop and conferences:

Four Steering Group meetings will be held in Sheffield and be attended by all team members, two service users and five experts in the field. These meetings are essential to ensure that the project meets its milestones and to ensure the full engagement with service users and experts. Rail and local travel costs (e.g. buses/taxis) are included at £45 p/person (8 people) p/meeting. Note that some members will be taking part via skype. Total: £1,680

Six team or analytic meetings, to be attended by some or all team members (see Timetable). Where possible we have doubled-up meetings to save costs and ensure value for money. For example, the first team meeting will take place on the same day as the first SG meeting. Over and above the funding requested above, two additional journeys are requested for the PI to visit York for team meetings. Funding for PC to attend the final steering group and team meeting is also requested. In addition, funding is requested for the statistical consultant, EU, to attend two analytic meetings in York. Total: £415.

Three service users' group meetings will be held, with three service users and two team members. These will take place in Sheffield, where the services users live. Funding is therefore requested for the two team members to travel from York. Total: £270.

Two dissemination workshops will be organised, to be attended by all team members plus two service users, to ensure that the results of the project are shared widely. Travel expenses (travel for 3 research team members and 2 service users are requested @ £45 each for each event. Total: £450.

Funding is requested for attendance at two conferences to ensure wide dissemination of findings:

- i) CJ or MT to attend The British Sociological Association (BSA) Medical Sociology Group conference attendance - fee: £360; 2 nights accommodation: £200; travel: £190 (£150 rail travel, £40 taxis). Total: £750
- ii) MR to attend Meeting of the European Neurological Society (taking place in Berlin, 2015) - fee - £550; travel (flights and transfers) - £300; 4 nights accommodation - £400. Total: £1,250.

Other Direct Costs

Expenses and payments for service users attending the Steering Group in line with INVOLVE guidance @ £150 p/person p/meeting & £100 p/person for the dissemination events. Total: £1,600.

Expenses and payments for service users attending Service Users' Group meetings in line with INVOLVE guidance @ £50 p/person p/meeting. Total: £855.

Two dissemination workshops will be organised to share the findings of the project with a wide audience. Room hire, catering and printing @ £750 per event. Total: £1,500.

There are no NHS Support or Excess Treatment Costs due to the nature of the project.

Planned or active related research grants

The proposed study builds on MR areas of clinical expertise and specialist interest in how best to communicate with patients about treatment. MR has lead two related projects using CA to investigate other aspects of decision-making, including how patients choose a drug for multiple sclerosis and how clinicians 'sell' psychotherapy to patients with functional neurological symptoms. The study also builds on MT's use of CA to study patient choice in recruitment to medical trials; talk about diagnostic testing in the neurology clinic; and effective communication strategies in other institutional encounters (e.g. the Jobcentre). CJ is applying to HS&DR 15 to fund a project on shared decision-making in childbirth. All co-applicants have contracts, which include dedicated research time, and have factored the proposed study into their planned workloads for 2014-2016.

References

1. Elwyn G, Miron-Shatz T. Deliberation before determination: the definition and evaluation of good decision making. *Health Expectations* 2010;**13**(2):139-47 doi: 10.1111/j.1369-7625.2009.00572.x[published Online First: Epub Date].
2. Department of Health. NHS Choice Framework 2013/14. London: HMSO, 2013.
3. Department of Health. Equity and Excellence: Liberating the NHS. Secondary Equity and Excellence: Liberating the NHS 2010.
4. Department of Health. NHS Constitution. Secondary NHS Constitution 2013.
5. Nicholson D. Secondary 2014.
6. Makoul G, Clayman M. An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 2006;**60**:301-12
7. Barnett J, Ogden J, E. D. The value of choice: a qualitative study. *Brit J Gen Pract* 2008;**58**:609-13
8. Charles C, Gafni A, Whelan T. Shared Decision-Making in the Medical Encounter: What Does it Mean? (or it Takes at Least Two to Tango). *Social Science & Medicine* 1997;**44**(5):681-92
9. General Medical Council. Good Medical Practice. Secondary Good Medical Practice 2013.
10. Elwyn G, Scholl I, Tietbohl C, et al. "Many miles to go...": a systematic review of the implementation of patient decision support interventions into routine clinical practice. *BMC Med Inform Decis Mak* 2013;**13**(Suppl 2):S14
11. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. *The qualitative researcher's companion* 2002:305-29
12. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, eds. *Analysing Qualitative Data*. London: Routledge, 1994:173-19.
13. Gale N, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology* 2013;**13**:117
14. Heritage J, Robinson JD, Elliott MN, et al. Reducing Patients' Unmet Concerns in Primary Care: the Difference One Word can Make. *Journal of General Internal Medicine* 2007;**22**(10):1429-33

15. Antaki C, Finlay W, Walton C, et al. Offering choices to people with intellectual disabilities: an interactional study. *J Intell Disabil Res* 2008;**52**(12):1165-75
16. Toerien M, Shaw R, Duncan R, et al. Offering patients choices: a pilot study of interactions in the seizure clinic. *Epilepsy and Behavior* 2011;**20**(2):312-20
17. Toerien M, Shaw R, Reuber M. Initiating decision-making in neurology consultations: 'recommending' versus 'option-listing' and the implications for medical authority. *Sociology of Health and Illness* 2013;**35**(6):873-90
18. Lee Y-Y, Lin JL. Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes. *Social Science & Medicine* 2010;**71**(10):1811-18 doi: <http://dx.doi.org/10.1016/j.socscimed.2010.08.008>[published Online First: Epub Date].
19. Drought TS, Koenig BA. "Choice" in End-of-Life Decision Making: Researching Fact or Fiction? *The Gerontologist* 2002;**42**(suppl 3):114-28 doi: 10.1093/geront/42.suppl_3.114[published Online First: Epub Date].
20. Fotaki M. Are all consumers the same? Choice in health, social care and education in England and elsewhere. *Public Money & Management* 2009;**29**(2):87-94 doi: 10.1080/09540960902767956[published Online First: Epub Date].
21. Greener I. Are the assumptions underlying patients choice realistic?: a review of the evidence. *British Medical Bulletin* 2007;**83**(1):249-58 doi: 10.1093/bmb/ldm024[published Online First: Epub Date].
22. Harding AJE, Sanders F, Lara AM, et al. Patient Choice for Older People in English NHS Primary Care: Theory and Practice. *ISRN Family Medicine* 2014;**2014**:6 doi: 10.1155/2014/742676[published Online First: Epub Date].
23. Levinson W, Kao A, Kuby A, et al. Not all patients want to participate in decision making. *Journal of general internal medicine* 2005;**20**(6):531-35
24. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science and Medicine* 1999;**49**:651-92
25. Nam KP, Gong HS, Bae KJ, et al. The Effect of Patient Involvement in Surgical Decision Making for Carpal Tunnel Release on Patient-Reported Outcome. *The Journal of hand surgery* 2014;**39**(3):493-98
26. Ryan J, Sysko J. The contingency of patient preferences for involvement in health decision making. *Health care management review* 2007;**32**(1):30-36
27. Hudak PL CS, Raymond G. . How surgeons design treatment recommendations in orthopaedic surgery. *Social Science and Medicine* 2011;**73**(7):1028-36
28. Pilnick A. 'It's something for you both to think about': choice and decision making in nuchal translucency screening for Down's syndrome. *Sociol Health Ill* 2008;**30**(4):511-30 doi: 10.1111/j.1467-9566.2007.01071.x[published Online First: Epub Date].
29. Stivers T. Parent Resistance to Physicians' Treatment Recommendations: One Resource for Initiating a Negotiation of the Treatment Decision. *Health Communication* 2005;**18**(1):41-74
30. Stivers T. Non-Antibiotic Treatment Recommendations: Delivery Formats and Implications for Parent Resistance. *Social Science & Medicine* 2005;**60**:949-64
31. Stivers T. *Prescribing Under Pressure: Physician-Parent Conversations and Antibiotics*. Oxford: Oxford University Press, 2007.
32. Ijäs-Kallio T RJ, Peräkylä A. . 'Unilateral' decision making and patient participation in primary care. *Communication and Medicine* 2011;**8**(2):145-55
33. Maynard DW, Hudak PL. Small talk, high stakes: Interactional disattentiveness in the context of prosocial doctor-patient interaction. *Lang Soc* 2008;**37**(5):661-88 doi: 10.1017/s0047404508080986[published Online First: Epub Date].
34. Costello BA, Roberts F. Medical Recommendations as Joint Social Practice. *Health Communication* 2001;**13**(3):241-60
35. Monzoni CM, Duncan R, Grunewald R, et al. Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. *Patient Educ Couns* 2011;**85**:189-200

36. Dixon-Woods M. Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine* 2011;**9**
37. Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol* 2009;**9**:59 doi: 10.1186/1471-2288-9-59[published Online First: Epub Date]].
38. Smith J, Firth J. Qualitative data analysis: the framework approach. *Nurse Researcher* 2011;**18**(2):52-62 doi: 10.7748/nr2011.01.18.2.52.c8284[published Online First: Epub Date]].
39. Ward DJ, Furber C, Tierney S, et al. Using Framework Analysis in nursing research: a worked example. *J Adv Nurs* 2013;**69**(11):2423-31 doi: 10.1111/jan.12127[published Online First: Epub Date]].
40. Carroll C, Booth A, Cooper K. A worked example of best fit framework synthesis: A systematic review of views concerning the taking of some potential chemopreventive agents. *BMC Medical Research Methodology* 2011;**11**
41. Swallow V, Newton J, Van Lottum C. How to manage and display qualitative data using 'Framework' and Microsoft® Excel. *Journal of Clinical Nursing* 2003;**12**(4):610-12 doi: 10.1046/j.1365-2702.2003.00728.x[published Online First: Epub Date]].
42. Drew P, Chatwin J, Collins S. Conversation analysis: a method for research into interactions between patients and health-care professionals. *Health Expectations* 2001;**4**:58-70
43. Robinson JD, Heritage J. Physicians' opening questions and patients' satisfaction. *Patient Educ Couns* 2006;**60**(3):279-85
44. Collins S, Drew P, Watt I, et al. 'Unilateral' and 'Bilateral' Practitioner Approaches in Decision-Making about Treatment. *Social Science & Medicine* 2005;**61**:2611-27
45. Drew P, Toerien M, Irvine A, et al. A study of language and communication between advisers and claimants in work focused interviews. In: 633 DfWaPRR, ed. Norwich: HMSO, 2010.
46. Heritage J, Maynard DW. *Communication in Medical Care: Interactions between Primary Care Physicians and Patients*. Cambridge: Cambridge University Press, 2006.
47. Heritage J. Conversation analysis at century's end: practices of talk-in-interaction, their distributions, and their outcomes. *Research on Language & Social Interaction* 1999;**32**(1-2):69-76
48. Heritage J, Robinson JD. The structure of patients' presenting concerns: physicians' opening questions. *Health Commun* 2006;**19**(2):89-102 doi: 10.1207/s15327027hc1902_1[published Online First: Epub Date]].
49. Robinson JD. The role of numbers and statistics within conversation analysis. *Communication Methods and Measures* 2007;**1**(1):65-75
50. Meakin R, Weinman J. The 'Medical Interview Satisfaction Scale'(MISS-21) adapted for British general practice. *Fam Pr* 2002;**19**(3):257-63
51. Robinson JD, Heritage J. The structure of patients' presenting concerns: the completion relevance of current symptoms. *Soc Sci Med* 2005;**61**(2):481-93 doi: 10.1016/j.socscimed.2004.12.004[published Online First: Epub Date]].
52. Rossano F. Gaze in conversation. *The handbook of conversation analysis* 2013:308-29